Oral health care and oral health-related quality of life of frail and care-dependent older people

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Most things that count are uncountable

Contents

Chapter 1

General Introduction

Introduction

Population ageing refers to both the increase in the population's proportion of older people and the increase in the average (median) age of the population and is now happening in almost every country worldwide [1]. Between 2015 and 2030, the number of people in the world aged 60 years and over is expected to grow from 901 million to 1.4 billion, and to more than double its size by 2050, reaching nearly 2.1 billion. The number of people aged 80 years or over is growing even faster and is expected to be tripled in number by 2050, to 434 million.[1] Likewise, the number of people of 65 years and over in the Netherlands is expected to increase from 2,4 million in 2008 to 4,2 million in 2040 while the total population count will remain stable [2]. Population ageing has major implications for nearly all sectors of society, in particular the health sector, and warrants political and economical choices concerning sustainable health care approaches.

A growing part of older people is frail. Between 2010 and 2030, the number of frail people aged 65 years and over in the Netherlands is expected to grow from just under 700,000 to more than one million [3]. Although there are many definitions of 'frailty' in use, most of these include the same constituents: a state of reduced psychological, physical or social reserve in combination with an increased risk for adverse outcomes such as falls, disability, institutionalization and death [4]. In this thesis, the integral definition that was constructed by an expert panel will be used: 'frailty is a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes' [5]. Populations that are captured within this broad definition of frailty partly overlap with populations with multi-morbidities, functional disabilities, and with care-dependent populations.

Care-dependency in this thesis is interpreted as a situation in which 'the self-care abilities of a person in terms of their daily physical and psychosocial

human needs have decreased to such an extent that the person's care demands are, to some degree, dependent on professional support' [6]. In the Netherlands, based on data from the Dutch National Center for Indication of Care Need (Centrum Indicatiestelling Zorg) that assigns health-based indications of need for professional support to individuals, in 2014 around 439.000 people had a somatic or psychogeriatric indication of care need, 91% of which related to people of 65 years and over [7]. In order to target the elderly population that is most likely to experience challenges with regard to maintenance of oral health, this thesis focuses on frail people who are care-dependent, as indicated by a health-based indication of need for professional support.

Oral health of older people

Studies worldwide have shown that the oral health of frail and care-dependent older people, both home-dwelling and institutionalized, leaves much to be desired [8]. A recent doctoral thesis on oral health of frail elderly in the Netherlands has shown that oral health among dentate nursing home residents was poor (72% had poor oral hygiene, 70% had carious teeth and 62% had fractured teeth). The oral health situation among home-dwelling frail older people was about as poor: 53% had poor oral hygiene, 54% of dentates had caries and the majority (75%) of edentulous wearers of complete removable dental prostheses (CRDPs) had ill-fitting CRDPs or wore no prostheses at all. Only 31% of the patients made routine dental check-up visits [9].

For adults in general as well as for older people, the most prevalent oral diseases are caries and periodontal diseases. Older people often demonstrate an increased risk of caries lesions, in particular at root surfaces (root caries) [10, 11]. Poor oral health is particularly important in older people, since risk factors and oral diseases have accumulated throughout life course. There is abundant evidence that poor oral health not only affects quality of life, but also general health of older people [12]. In geriatric populations, impaired oral

health can eventually lead to life-threatening conditions, including malnutrition and dehydration [13, 14], brain abcesses [15], valvular heart diseases [16], joint infections [17], cardiovascular disease [18], and pneumonia [19]. Apart from potential life-threatening effects, bad oral health can cause pain, impaired flavor, and bad breath, while ill-fitting dentures can cause irritation and difficulties with chewing or biting [20]. Toothache, difficulties with eating, damaged teeth and especially tooth loss can also give rise to embarrassment and hence impede not only physical but also psychological and social functioning [21-26].

Impaired health, oral health, and oral health related quality of life

Impaired health, including frailty and care-dependency, and oral health mutually influence each other. Poor oral health can increase frailty through decline of oral functions, hygiene, and nutritional state [12]. Conversely, frail older people are particularly vulnerable to oral disorders, due to the complex interaction between oral health, systemic diseases, the use of medication and failing upkeep of oral hygiene [27, 28]. Besides, frailty tends to alter the experience, perspectives and attitudes with regard to health in general [29],[30],[31] and will most likely change the value adhered to oral health, which in turn may change self-perceived dental care needs.

How and why these values change, although vital to the planning of oral health care services, has hardly received any attention in dental literature. To our knowledge, only two studies that address this issue have been published [32, 33]. In a study by MacEntee [32] participants emphasized the need to adapt as an integral part of successful ageing and a means of coping with the impact of oral disorders. Likewise, Brondani e.a. [33] found that older people could accept some oral impairment and disability by balancing gains and losses, adjusting expectations, and seeking social support.

These studies, however, did not take the influence of (the level of) frailty into account. Frailty may increase acceptance and coping, and change frames of reference against which ageing people assess their oral health. The effects of

coping and adaptation mitigate negative impacts of (oral) health disorders on older people [12, 34].

Studies on associations between frailty or care-dependency, or, less specifically, impaired general health status, and oral health-related quality of life (OHRQoL) show contradicting results [35-43]. For instance, Jensen e.a. [35] found no association between OHRQoL and performance in activities of daily living (ADL), while Miura e.a. [36] found a significant positive association between OHRQoL and ADL, especially communication. Ostberg e.a. [37] showed that OHRQoL was significantly associated with self-rated general health and self-rated mental health, but not with self-rated physical health, whereas Hassel e.a. [43] found a significant inverse association between physical pain and OHRQoL. Similar inconsistent findings have resulted from research on the associations between general health and quality of life (e.g.[31, 44, 45]). Clearly, the associations between impaired health, OH and OHRQoL need further investigation.

Moreover, findings on OHRQoL of (frail) older people almost exclusively resulted from quantitative surveys that used standard 'oral health related quality of life' (OHrQoL) instruments like the OHIP (Oral Health Impact Profile)[46] or GOHAI (Geriatric Oral Health Assessment Index) [21]. These instruments can measure negative oral health impacts, but not a possibly positive or neutral experience of such negative oral impacts. For instance, not all people do mind when they cannot bite an apple because of loose teeth. Such a response could be a result of coping and adaptation [34, 47] and altered health expectations in old age [48]. It could also be due to a cohort effect, in that the generation that lived through world war(s) may have better coping skills than younger generations [49].

Yet these neutral or positive responses to negative OH impacts could help to elucidate the discrepancy between self-rated oral health status and related OHRQoL found in older people [48-50]. In this light, it is important to notice that existing evidence on the associations between OHRQoL and oral health of older people is controversial, with several studies indicating that the OHRQoL remains stable or even improves despite decreasing oral health [48-52], while others show a negative effect of decreasing OH on OHRQoL [8, 27, 53, 54].

Oral health care

Advances in oral health care and treatment in the past decades have resulted in a lower percentage of edentulous older people worldwide. At the same time, dentate people tend to preserve more teeth into older age. In the Netherlands, the percentage of dentate older people (65 years or over) increased from 42% in the year 2000 to 59% in 2009 (CBS Statline). This pattern, in combination with growing numbers of older people at a rate of 25% in this period, leads to increased preventive and curative treatment needs for older people [8].

Research has, however, shown that a considerable number of frail older people is not capable of maintaining a level of oral self-care that supports or improves the level of oral health [8]. Several barriers to older people's use of dental health care services have been proposed: lack of perceived need, fear, perceived lack of availability of services, characteristics of the dental practitioner, poor (general) health, difficulties in accessing dental services, and costs [55, 56]. Barriers to oral self-care include lack of perceived need, lack of prioritization of frail people and their caregivers, impaired mobility, dexterity and declining cognitive abilities [28, 57-59].

Apart from the effect of cognitive disorders [60], it has not been investigated to what extent frailty-related factors influence oral health care behavior of older people. Nor has it been studied which factors motivate frail older people to apply oral care. Bedos [61] so far has produced the only evidence on such motivating factors in a study targeting people that received social support. Decline of their dental appearance and its devastating impact on self-esteem, social interaction, and employability were the most prominent motivating factors for this group. Factors that motivate frail older people to apply oral care can be assumed to be somewhat different, since they are at a different life stage and involved in a process of health decline that most likely changes their priorities in life.

Justification and relevance

When combined, the aforementioned facts and developments in demographic trends and oral health care for frail older people pose a challenge to oral health care systems in the Netherlands and worldwide. The Dutch Ministry of Health, Welfare and Sport has concluded from several reports and signals from the health care sector that the group of frail older people does not receive the oral health care that it needs [62, 63]. This leads to loss of functionality and an early call for long-lasting care. This national trend reflects a global trend [8] and calls for action.

Hence, innovative approaches to oral health care for frail older people that will result in better oral health of the target group and are economically feasible, are currently being sought [64, 65]. Such approaches should be in line with the current paradigm of patient-centered care in order to optimize health outcomes [66]. Indeed, over the last two decades, the patient's perspective has become increasingly important to the decision to apply dental treatment and has become more and more leading in the design of treatment and care plans [25].

The oral health paradox of better self-perceived oral health at older age despite equal or worse clinical oral health conditions [49], underpins the assumption that older people form a distinct group. Typical of this group is that the patient's life perspective and related needs are likely to result in different self-perceived oral health needs than in other groups, and treatment preference is strongly influenced by people's perception of oral health [61]. The fundamental question for care staff and dental professionals should be: "Does the care- or treatment burden outweigh the expected improvement in oral health and oral health-related quality of life?" In order to answer that question, more needs to be known about which oral health views and expectations exist among this group and care-professionals and how these relate to oral health factors and quality of life.

In addition, clinical and self- perceived oral health, clinical and self-perceived oral health needs, and oral health care attitudes and practices of frail and care-dependent older people should be assessed in order to be able to estimate the effectiveness of new oral health care approaches. Therefore, the deficiencies and barriers with regard to the upkeep of oral hygiene and dental service use, need to be identified for frail elders.

In the Netherlands, the views and attitudes of older 'patients' on oral health and oral health care behavior are largely unexplored. Up-to-date information on OHRQoL is very scarce for frail Dutch older people and the same applies to information on received oral care and oral care needs as perceived by both the target group and professionals. Recent information on their oral health status is also limited, but has recently be supplemented by Hoeksema e.a., as reported above [9]. These findings concur with epidemiological data on older people in three Dutch care homes [67], who had high (unmet) treatment needs although virtually no complaints were reported.

The studies presented in this thesis yield information on views and attitudes of older people with regard to oral health care, related behavior and oral health-related quality of life. Identification of factors that play a vital role in oral health care behavior will help to better tailor oral health care modalities to the situation of the target group, comprising of people of 65 years and over who are frail and care-dependent.

Objectives

The overall objectives of this study are, with regard to a population of older people who are frail and care-dependent:

- To gain understanding of people's experiences, perceptions and attitudes with regard to oral health, received oral health care, barriers to obtaining oral health care, and oral health-related quality of life

- To assess the relations between oral health care behavior, oral health outcomes including oral health-related quality of life, oral health needs, and frailty-related factors.

Specific objectives are:

1. To qualitatively assess the impact of having natural teeth on QoL and the role of frailty in this relationship (Chapter 2)
2. To qualitatively assess the impact of frailty on oral care behavior and to identify barriers and motivating factors with regard to oral self-care and dental service use (Chapter 3)
3. To translate and validate a Dutch version of the GOHAI (Geriatric Oral Health Assessment Index) (Chapter 4)
4. To explore the associates of OHRQoL in a care-dependent and care-independent population (Chapter 5)
5. To assess the associations between oral care behavior and frailty-related factors in a care-dependent population (Chapter 6)

Outline of the thesis

Chapter 1 is the general introduction.

Chapter 2 describes the impacts of having natural teeth on the QoL in frail and care-dependent dentate older people and the role of frailty in this relationship. Information was obtained through qualitative in-depth interviews with elders of varying frailty in residential aged care facilities and daycare centers in East-Netherlands.

Chapter 3 describes how the type and level of frailty affect the oral self-care behavior and dental service use, as well as oral health perspectives of frail and care-dependent older people. To this purpose, barriers and motivating factors with regard to oral self-care and dental service use were investigated. Again, qualitative in-depth interviews were used, targeting both dentulous and edentulous frail older people.

Chapter 4 presents the results of the translation and testing of the validity and reliability of the GOHAI (Geriatric Oral Health Assessment Index). The GOHAI is especially designed for older people and is one of the most frequently used instruments to measure OHRQoL of adults internationally. The GOHAI was translated into a Dutch version (GOHAI-NL) and tested separately in care-independent and care-dependent older people.

In Chapter 5, the associates of OHRQoL in a care-dependent and care-independent population are explored. To this end, the relationships between oral health factors and general health factors (including physical, mental, and social health domains) and OHRQoL were examined in a care-independent and a care-dependent older population.

Chapter 6 presents associations between oral care behavior and frailty-related and other factors in a care-dependent population. It provides an answer to the question which factors are associated with oral health care behavior, in particular the frequency of dental service use and of tooth brushing and cleaning of dentures, and with changes in oral health behavior after the onset of care-dependency

Chapter 7 presents the general discussion, and includes integrated main findings, reflections on and implications of these findings, and reflections on study design. This chapter ends with general conclusions and recommendations for various stakeholders.

Chapters 8 and 9 provide the respective English and Dutch thesis summaries.

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Chapter 2

The impact of having natural teeth on the quality of life of frail dentulous older people. A qualitative study

This chapter is an edited version of the published article: The impact of having natural teeth on the QoL of frail dentulous older people. A qualitative study. Dominique Niesten, Krista van Mourik and Wil van der Sanden. *BMC Public Health* 2012,12:839

Abstract

Background: In order to adapt oral care and treatment to the demands of the growing group of frail dentulous older people, it is important to understand how and to which extent having natural teeth contributes to the quality of life (QoL) of frail older people and how frailty influences their perspective.

Methods: A qualitative approach was used. Interviews with 38 Dutch frail older dentulous people were tape-recorded, transcribed, coded for content and analyzed. Additional information was collected which included age, gender, living situation, use of dental prostheses, self-reported oral health status, chronic disorders, and an index for frailty.

Results: Seven themes were identified in the relationship between natural teeth and the QoL of the participants: pride and achievement; intactness; sense of control; oral function; appearance; comfort; along with coping and adapting to disabilities. Having natural teeth generally had a positive effect on QoL. Positive effects through pride and achievement, intactness, and sense of control were most apparent for the most severely frail. They compared themselves with peers who are more often edentate, and valued the good state of their teeth against the background of their declining health, especially those with disabilities causing severe chronic pain or impaired fine-motor skills. The effect of coping with and adaptation to tooth loss was also most apparent for the most severely frail. There was a gender effect in that the men generally cared less about having natural teeth than women, regardless of their level of frailty.

Conclusions: QoL of frail older people is positively influenced by natural teeth, and this effect seems to increase with increasing frailty. Preservation of teeth contributes to a positive body image and self-worth. Oral care for frail people should aim to preserve natural teeth if possible.

Introduction

The type and level of oral health care that is currently provided for the fast growing group of frail dentulous older people is not tailored to their treatment needs and demands [1,2]. Since more older people retain their natural teeth, the objective need for dental treatment for this group increases. This applies in particular to frail people, since medication use, systemic diseases and a weakened physical and cognitive condition make frail people more vulnerable to the impact of oral disorders [3,4]. Frailty, being "a state of reduced psychological or physical reserve in combination with an increased risk for adverse outcomes such as falls, disability, and institutionalization" [5] is likely to change the experience of health in general [6-8]. Likewise, frailty is expected to change the value that people ascribe to their oral health and to having natural teeth, and will consequently influence subjective dental care needs and demands.

Associations between frailty and oral health related QoL have been studied [9-11], but mostly with quantitative surveys where standard oral health related QoL (OHRQoL) instruments, such as the Oral Health Impact Profile (OHIP) [12] or the Geriatric/General Oral Health Assessment Index (GOHAI) [13] were used. These instruments focus almost exclusively on the negative impacts of oral disease [14,15] and thus fail to assess the positive contribution that natural teeth can make to QoL. Another limitation of the instruments is that they do not identify positive or neutral attitudes to oral health despite negative oral health impacts. For instance, not all people avoid social situations when they miss a front tooth. This may be due to changed expectations of health in old age [16], coping and adaptation strategies [17,18], or a generational effect in people who experienced much hardship during their formative years, especially among the "war generation" who may be more resilient to change than younger people (19). These positive attitudes could provide an explanation for the discrepancy between self-rated oral health status and OHRQoL measures [16,19,20].

Coping, adaption and expectancy generally have a stronger effect with increasing age and frailty to influence the personal and dynamic nature of QoL (18). The WHO has defined QoL as "*an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*" [21]. Locker [22], Bowling [23] and Browne [24] have argued that QoL has primarily meaning at a personal level, and that related domains of significance should be determined individually for everyone to gain deeper insights to the impacts of specific health aspects (like having natural teeth) on QoL.

The relationship between natural teeth and QoL has been addressed in several enquiries conducted either with psychometric instruments [9,20,25-27], or by personal open-ended interviews [28,29]. Most participants in MacEntee's study [28] indicated that they wished to maintain their natural teeth as long as they did not cause problems. This finding was supported by surveys elsewhere showing that higher numbers of natural teeth [9,20,26,27], and higher numbers of occluding pairs of natural teeth [30] are associated with better OHRQoL scores. Likewise, studies on tooth loss [31-33] showed that loss of teeth often negatively influences QoL of older people, e.g. through impaired eating function, lowered self-confidence, and dislike of appearance.

However, it is not yet clear *how* having natural teeth contributes to the QoL of frail older people, nor has the influence of frailty in this relationship been assessed. This knowledge, together with other relevant information, will help to identify frail elderly who are likely to benefit most, in terms of QoL, from oral care support or treatment, and thus allocate resources more efficiently.

Consequently, we posed the following research questions: "How do natural teeth contribute to the QoL of dentulous people who are elderly and frail" and "How does frailty influence the impact of having natural teeth on QoL".

Methods

Since our research questions target the experiences and perspectives of frail older people with regard to having natural teeth and QoL, a qualitative approach through open-ended interviews was appropriate [34,35]. We used a purposive sampling strategy in order to optimize diversity in responses to our research questions [36]. Hence we selected individual men and women of different ages, cultural background, and different levels of frailty [9,37,38].

Two trained interviewers (DN, KM) conducted open ended interviews. They made 'field-notes' immediately after each interview to record their personal reflections on the interview and on extraneous events that might have influenced the interview.

Setting and participants

Within the group of frail older people, we targeted those for whom issues in relation to oral health were expected to be most manifest, i.e. people who could not fully function independently as evidenced by a medical indication for professional care support. Consequently, Residential Aged Care Facilities (RACFs) and regular daycare centers in the Arnhem-Nijmegen region, East-Netherlands, were randomly chosen from a national website that lists all Dutch care institutes (www.zorgkaartnederland.nl/).

Most of the care-managers we contacted, agreed to participate. We asked them to identify potential participants according to the type and intensity of care they receive, based on the classification used by the Dutch National Centre for Indication of Care Need (CIZ). Each resident is assigned a 'care level package' (CLP, in Dutch: Zorgzwaartepakket, ZZP) by a medical authority, indicating the level and type of care needed and referring to impairments in the physical and/or mental and/or social domain (Table 1). Care level and type of care level package 1 is equated

with mild frailty in this study; package 2 and 3 with moderate frailty and package 4-6 with severe frailty.

We excluded residents with care level packages 7–10 because their health status is beyond 'frail': They are either completely functionally dependent, cognitively disabled, or receive rehabilitative or end-of-life care. Substitutes for missing CLP scores were derived through consultation with the care-manager and based on the table above.

Table 1. Type and intensity of care according to Care Level Package (CLP)

CLP	Assistance		Care			Medical care	Behavioural disorders	Care indication Hours/wk
	Special coping	Psychosocial functioning	Personal care	Mobility	Motoric functioning			
1	+	0	+	+	0	0	0	3-5
2	+++	+	++	+	+	+	0	5,5-7,5
3	++++	++	++++	+++	++	+	0	9,5-11,5
4	++++	+++	++	+	+	+	+	11-13,5
5	+++++	++++	++++	++++	++	+	+	16,5-20
6	++++	+++	+++++	+++++	+++	++	0	16,5-20

0 means that no care is needed in the referred category. ++ = coaching needed; ++++ = support needed; ++++++ = staff taking over. *Zorgzwaartepakketten (care level package). Source: V&V Enschede 2010 PJ/10/1657/imz.

We included residents who were 65 years and over, had at least four natural teeth, were cognitively alert and consented in writing to participate. According to the care-managers, almost all of the recruits consented to participate; reasons for non-participation were not communicated. All of the participants before they were asked to sign the Consent Form were informed about the purpose of our study and the methods we would use to interview them and analyze the results as approved by the Medical Ethics Committee (CMO) of the Radboud University Nijmegen Medical Center Nijmegen CMO (ref. 2009/153).

Interviews

Depending on the wish of the participant, interviews took place at a separate room in the daycare centre or assisted living homes, or at

people's own rooms or homes. Confidentiality and anonymity were guaranteed at the start of the interview. Interviews were audio-taped, transcribed verbatim and anonymized.

An interview guide was used by the interviewer to prompt questions about: (i) self-reported oral and general health; (ii) the meaning of QoL; and (iii) the significance of natural teeth. Participants were encouraged to give as much information as possible in response to these issues and raise any further related topic. Additional data were collected on each participant's age, gender, chronic disorders, use of dental prostheses, and type and intensity of received care.

Data analysis

The data were analyzed using thematic analysis: The interviewers analyzed the verbatim transcripts of interviews to identify specific themes and the context in which the themes influenced the participant's QoL and feelings about natural teeth [36].

The interviewers independently coded each transcript line-by-line, before discussing and reviewing the attributes and meaning of the codes until consensus was reached. The coding frame developed throughout the process of data analysis. We used a computer-software program (MaxQDA 2007; www.MaxQDA.com) to help keep track of the coding and to enable (semi-) quantification during the analysis. A third investigator (WS) checked the reliability of the codes on a random selection of five interviews. Finally, we grouped codes into conceptual themes, which were iteratively checked against the data, refined, and discussed among all authors until we agreed about a final set of themes.

Quotes that best illustrated these themes, or points of distinction within themes, were translated into English, and are included in the 'results' section below.

We examined the contribution of having natural teeth to QoL in two ways: by directly asking participants what they felt about natural teeth and QoL; and by identifying, analyzing and comparing segments of text that explicitly or implicitly addressed the value of having natural teeth. Likewise, we assessed how frailty influenced the relation between having natural teeth and QoL in two ways: by comparing the transcripts of participants with different levels of frailty; and by identifying, analyzing and comparing segments of text that explicitly or implicitly addressed the role of frailty. In this context we distinguished between slight frailty, moderate frailty, and severe frailty.

Trustworthiness and reliability

We used several triangulation methods to ensure the trustworthiness and reliability of our analysis [39]. Investigator triangulation was achieved through having three researchers analyze the data and discuss interpretations. Within-method triangulation was achieved through combining the findings of observational notes, interviews, and, occasionally, short feedback sessions with contact persons. Reliability was further enhanced through the consistent use of techniques such as paraphrasing and summarization for clarification during the interviews (36) and by increasing the credibility of interpretations through the use of participants' quotes and in-vivo codes and (sub) themes [40].

Reflection on the role of researchers

The research group comprised a multidisciplinary team with extensive experience in and knowledge of qualitative methodology, health sociology and medical anthropology, philosophy, and with both academic and (dental) clinical expertise. Data analysis was thus influenced by knowledge and experience from varying academic and professional backgrounds.

Table 2. Characteristics of participants

	Gender	Age	Ethnic group*	Cardio vascular diseases	Arthritis/rheuma	Diabetes	Cancer	COPD**	Psychological dysfunction	Parkinson	Paralytic	Other (e.g. auditive or visual Impairment)	Impaired fine motor skills	Impaired gross motor skills	CLP (Care Level Package)	Dental status
1	F	69	C		x									x	1	RPD
2	M	69	C				X								1	N
3	F	76	M	x		x									1	N
4	F	80	C											x	1	CUD
5	F	75	C	x											1	RPD
6	M	84	C									X			1	C+R
7	F	80	C	x										x	1	N
8	M	72	C	x	x	x									1	RPD
9	F	86	C		x	x									1	N
10	M	72	C						x						1	RPD
11	M	69	C				X								1	N
12	M	88	C		x									x	2	N
13	F	78	C						x						2	CUD
14	F	85	C	x			X								2	C+R
15	M	79	C	x								X		x	2	C+R
16	M	67	C						x						2	C+R
17	F	84	C						x					x	2	N
18	F	79	C						x					x	2	CUD
19	F	94	C									X		x	2	CUD
20	F	84	C	x	x							X		x	2	C+R
21	F	72	C								X	X		x	3	RPD
22	F	83	C					x						x	3	CUD
23	M	78	C		x						X	X	x	x	3	RPD
24	F	69	C		x							X		x	3	N
25	M	80	C							x			x	x	4	RPD
26	F	90	C									X		x	4	RPD
27	F	97	C		x						X			x	4	N
28	F	93	C	X				x				X	x	x	4	RPD
29	F	93	C						x		X			x	5	N
30	F	84	C	X					x			X			5	RPD
31	F	79	M						x					x	5	N
32	F	85	C		x						X			x	6	CUD
33	F	70	C							x			x	x	6	N
34	F	83	C						x					x	6	N
35	F	82	C						x					x	6	RPD
36	F	88	C						x		X			x	6	N
37	F	77	C		x								x	x	6	N
38	M	65	C		x				x		X	X	x	x	6	CUD

*C= Caucausian, M = Mongoloid; **Chronic Obstructive Pulmonary Diseases; Dental status: RPD= removable partial denture(s), CUD = complete upper denture, C+R = complete upper denture and removable partial denture(s), N = natural teeth only

Consultation of geriatric dentists and geriatric nurses during the study set up helped us to raise appropriate issues during the interviews, and to better understand the context of responses. The only dental professional of the team did not conduct the interviews.

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The research group comprised a multidisciplinary team with extensive experience in and knowledge of qualitative methodology, health sociology and medical anthropology, philosophy, and with both academic and (dental) clinical expertise. Data analysis was thus influenced by knowledge and experience from varying academic and professional backgrounds. Consultation of geriatric dentists and geriatric nurses during the study set up helped us to raise appropriate issues during the interviews, and to better understand the context of responses. The only dental professional of the team did not conduct the interviews.

Results

General

Participants were interviewed between March 2009 and August 2010. We stopped after 38 interviews when it was obvious that no new themes were emerging from our analyses (theme saturation) [34]. Apart from two women of Indonesian heritage (born Indonesians who moved to the Netherlands around their thirties), all of the 27 women and 11 men interviewed were of European heritage, and they lived either at home and frequented a daycare centre (n=18) or lived in assisted living homes (n=20). They had an average age of 79.9 years (65 – 97 yr), with varying degrees of frailty and a wide range of chronic disorders (Table 2). Most of them had removable partial dentures or complete upper dentures. Information on fixed dentures was not available for all participants and is therefore not included. Table 2 shows an overview of characteristics of all participants.

Quality of life

When asked about what constituted QoL for them, participants' initial replies varied from "*seeing my grandchildren twice a week*" and "*reading books*" to more general factors like "*being independent*" and "*good health*".

Participants' answers could be roughly divided into the domains physical health, psychological well-being, social participation, autonomy, and being active. Most participants mentioned at least two or three domains or related items. Health, autonomy and social participation were most frequently mentioned. Typically, the least frail put more emphasis on the importance of being healthy and less on participation; while generally it was the other way around for severely frail people:

> "*I like the fact that I can still walk up and down the alley with the rollator walker*. *That I don't need help when I go to the restaurant*. *That I can go out of my room and see people and do crosswords with a friend*, *that is very important to me*." (woman, 97, severely frail).

The realization that good health is unattainable for most severely frail people often moderated their 'priority list' relating to QoL.

> "*Good health*, *that is the most important good*, *but I will never have that anymore*. *Yet*, *I can still join all the parties that take place here*. *And I do get a lot of pleasure from that*. *Any time that something is going on*, *I join in*. *I do the conga in my wheelchair*." (woman, 77, severely frail).

When asked how having natural teeth contributed to what the participant thought a good QoL entailed, a variety of answers followed. Before analyzing these answers in detail, it is important to note that basically all participants saw oral health as a part of their general health, and only made a gradual rather than a principal difference between one and the other where impact on their QoL was concerned:

> "*A healthy mouth is very important to me*. *That has to do with the overall condition of my body*. *The mouth is part of a whole*." (man, 69, slightly frail).

Value of having natural teeth

It appeared that having natural teeth generally contributed to people's QoL in a positive sense. We identified six themes that addressed the relationship between having natural teeth and QoL: achievement and pride; sense of control; intactness; oral function; appearance and comfort. Furthermore, the mediating effects of adaptation and coping to experienced tooth decline or loss, and of acceptance of anticipated tooth decline or loss, emerged as a separate theme.

Achievement and pride

Having preserved natural teeth gave people a sense of achievement which inspired pride:

> "*Yes I do feel proud that I have been showing discipline in looking after my teeth*, *that I have always done my best to look after my teeth as well as I could*. *Many people are indifferent*, *careless*, *because it requires an effort*, *it is a hassle to look after your teeth*. *And I have overcome that aversion*." (man, 72, slightly frail).

Many participants across all frailty categories mentioned this sense of achievement and, in many cases, with pride by comparing themselves to peers who did not have their natural teeth. There was an assumption that people without natural teeth had not put in the same effort to preserve their teeth. This comparison with edentulous people seemed to generate even more pride for people with impaired motor skills:

> "*I do make the effort to brush* (*my teeth*) *every night*, *even though my hands give me awful pain*, *I suppose that is very brave of me*." (woman, 70, severely frail, severe Parkinson).

There was pride also in being exceptional compared to others of the same age or level of frailty by having natural teeth:

> "*I am quite proud to still have my own teeth*, *because everyone thinks I have dentures*. *And almost everybody does indeed have dentures here* (…). *Every nurse asked me where I left my dentures at night*. *I said*: "*I have no dentures"*. *They didn't believe it*. *It is very exceptional*, *it really is*." (woman, 77, severely frail, institutionalized).

This pride was expressed typically by participants who were severely frail and institutionalized, who compared themselves downwardly with others:

> "*I enjoy having preserved my teeth* (…) *because I have noticed that most people of my age have dentures*, *and even quite a few people who are much younger than I am*." (woman, 84, severely frail, institutionalized).

Most people said that retention of natural teeth was not only a matter of achievement but also a consequence of environmental factors and genes (several people mentioned that toothbrushes, toothpaste and particularly fluoridated toothpaste, had not been available to them until their late youth or early adulthood, due to the War and lack of money).

Participants who mentioned the influence of environmental factors and genes, still felt that 'good teeth' were an achievement due primarily to persistent and good oral care, and the awareness of this achievement, like the awareness of being exceptional, contributed to their sense of self-worth ('a reflection of a person's overall evaluation of his or her own worth' [41]) which was evidenced through comments like "*the fact that I still have my natural teeth does make me feel better about myself*." (woman, 97, severely frail, partially paralyzed, institutionalized).

Sense of control

A "*sense of control*" for the participants meant being responsible for maintaining good teeth.

> "*I'm happy that I can brush my own teeth. You do it for yourself, after all. You need to look after what you've got. That goes for the whole body. It is satisfying.*" (woman, 94, moderately frail).

They wanted to look after their teeth and linked their sense of control to their autonomy and independence, which were mentioned frequently as important contributions to QoL.

We identified two reactions to the *thought* of losing control: Acceptance of help for oral hygiene to preserve natural teeth, and a preference for dentures rather than being dependent on others to maintain natural teeth. The former was the dominant reaction, generally from women and others who were quite frail. Yet there was a difference between the thought of losing control and the experience of losing it. One younger woman with severe Parkinson disease, who had problems coping with and accepting her disease, indicated how losing control made her anxious:

> "*I want to keep doing everything myself, combing my hair, cutting my nails, brushing my teeth. Very often, I can't do it. And then I get very angry, very angry, even though I know that the nurses who do it for me can't help it* (. . .). *It's not good, I know.*" (woman, 70, severe Parkinson, severely frail).

A few people who suffered from physical pain caused by chronic complaints stressed the importance of maintaining some control over their teeth since they constituted a part of the body that they still controlled:

> "*I find it very important to maintain control over my own teeth. If you look at all that I had to give up. . . .so much. But I am still the boss over some parts of my own body. When I don't think it's a good idea to*

eat a sweet, *I won't take it*." (woman, 77, severe arthritis, severely frail).

Although the thought of losing control was accepted generally with less difficulty by severely frail participants, the idea of maintaining their natural teeth was particularly important against the backdrop of declining health. Control was related to oral health in general but also as something of value for itself. There was a more subtle feeling of responsibility for keeping *intact* body parts (such as teeth) healthy:

> "*I want to look after my teeth*. *They belong to me*. *And anything that belongs to me*, *I wish to take care for*." (woman, 84, moderately frail).

Assessment of natural teeth was not always purely positive because a few participants believed that it was easier to maintain dentures. However, the satisfaction of being able to maintain self-control far outweighed the inconvenience that it entailed.

Intactness

Numerous participants across all frailty categories mentioned that they felt good or wholesome when teeth were still intact, or incomplete when teeth were missing:

> "*It* (Missing my teeth) *is like something is lacking*; *it is not all complete anymore*, *isn't it*. (. . .) *That is a pity*, *I really do regret it*, *even though it doesn't cause me real trouble*." (man, 88, moderately frail, 3 molars missing).

and:

> "*I used to have good teeth*, *but I did not have the opportunity and the money to have them restored*, *which I regret*. *The better your body is preserved*, *the better you feel*." (woman, 85, moderately frail, complete removable dental prosthesis in upper jaw).

Several participants were upset to have lost natural teeth, even if the loss did not cause functional problems or if they had dentures, because they felt incomplete. A few, mostly male or severely frail, participants said that tooth-loss did not bother them. But, overall, the term 'false teeth' was considered pejorative, and the idea of removing them from the mouth somewhat revolting:

> "*I find it repulsive*, *when people take out their dentures*. *Or rinse them under the tap*, *brrr*." (woman, 76, slightly frail).

Natural teeth, in contrast, bestowed a sense of dignity "*I think that it* (keeping your natural teeth) *is part of being human*." Having preserved one's teeth gained importance against the background of a declining body for a number of severely frail people, especially for those with chronic pain and those who had problems accepting their poor health:

> "*Having your own teeth*, *that means*: *a bit of self-preservation*, *you feel better about yourself*. *It means preservation of that small part of your body*, *while the rest is collapsing*." (woman, 70, severe Parkinson, severely frail).

It was better, we heard, to have natural teeth because "*what is body-own is best*", and "*natural teeth always fit*, *because they belong to you*, *like your arms and legs*." Having natural teeth thus contributed to a more positive body image through feelings of bodily integrity and wholeness. Losing teeth, on the other hand, negatively changed perceptions pertaining to body image for several participants.

A mouth that functions

Oral function is an important domain within all oral health related QoL instruments and it is not surprising that basically everybody in this study mentioned the importance of a mouth that functions in relation to QoL. The contribution of natural teeth to oral function was often determined in contrast

with dentures. Many thought that good function is related to teeth being well fixed and fitted, and that dentures do not "fit" like natural teeth:

> "*If I would have full dentures*, *I expect that would be annoying*, *because of all the discomfort* , *that they would not fit well*, *that I wouldn't be able to chew*, *or eat properly*, *that they would be a bit loose*, *such things*." (man, 84, slightly frail).

The function most mentioned was eating, followed by talking. Smiling, kissing and laughing were also closely associated with QoL. One paraplegic man revealed some situational benefits of natural teeth:

> "*I do a lot with my mouth*, *like carrying things*. *When I need a milk carton from the fridge*, *I grab it with my teeth*. *If I would take it with my hands*, *it could easily fall* (…). *I have also seen other people in the rehabilitation clinic who cannot use their hands at all*. *They do a lot with their mouth*, *the ones that have strong own teeth like me*." (man, 78, tetraplegia, severely frail).

When assessed in relation to bodily decline, the requirement of a functional mouth in order to eat properly was also linked to dignity:

> "*There is this lady here*, *she does not have teeth*, *and no dentures either*. *She cannot eat half of what is being served*. *After every meal the edge of her plate is full of all the stuff she cannot bite*. (..) *However hopeless my body's condition is*, *I wish to eat properly*. *Otherwise my diet would be down to porridge*. *That would be horrible*." (woman, 77, severely frail).

There were however a few, mostly severely, frail participants who tolerated eating difficulties without complaint "*You only spend half an hour a day eating anyway*" (woman, 93, severely frail). Without exception, these were people who had been living with chronic disease for years and who

showed in their narratives a high degree of acceptance of their health situation.

A few participants, mostly severely frail men in institutions, said that the functionality of their natural teeth was the principal, if not only, reason for not having them replaced by artificial teeth. This opinion was expressed by people who generally seemed to accept their health decline and some decline of oral function without too much difficulty as an inevitable aspect of old age.

Appearance

For most participants, 'good appearance' equaled looking "*neat*" and "*well cared for*". Most people thought that natural teeth looked better than artificial teeth, but in case they would negatively affect their appearance, it was time to have them replaced:

> "*I would not like to smile at someone if my teeth would look bad. (....) Although I'd love to keep my own teeth, in that case I would rather have artificial teeth.*" *(woman, 69, moderately frail).*

The men were clearly less concerned than the women about their appearance and most mentioned that they found oral function much more important than dental looks. However, a typical response for the male and female severely frail was to consider their declining oral appearance in the perspective of their declining general health:

> "*I have my teeth the way they are*. *And yes they do get yellow*, *and yes they are not straight and neat anymore*. *But I do not mind*. *That is because I am not in good shape anymore*, *I think*. *I don't care what it looks like anymore*, *I'm only concerned with my health now*." (woman, severely frail, 83 year).

Indeed, the few women who seemed unconcerned about their appearance, seemed also quite accepting of their health decline and the

thought of death. A certain degree of decline in oral appearance was accepted by most respondents across all frailty categories:

> "*If you are 75 and you have a beautiful set of teeth*, *well that's a strange sight isn't it*? *I think that your face is allowed to show that you are not 20 or 30 anymore*, *no matter if it is about your teeth or your eyes or your skin*." (woman, 75, slightly frail).

However, if the decline passed a certain point, many participants saw it as unacceptable, which stresses the relevance of personal appearance even at a later age.

The women of Indonesian heritage strongly emphasized the value of their appearance and thought that they were more critical than Dutch people:

> "*The people here don't care about their teeth*. *They don't have nice teeth and they don't brush them*. *When I moved to Holland*, *it was striking that the Dutch have such bad teeth*. (…) *Whereas all people from Java*.. *their teeth are beautiful*." (woman, 79, severely frail).

Natural teeth were strongly related to body-image and several participants agreed that you "*get a different face when you have dentures*" (woman, 79, moderately frail), which was something they tried to avoid. Not only the internally constructed body-image (the way someone sees him/herself) but also the externally constructed body-image (the way someone perceives others see him/ her) and the body image of others could be affected by the looks of (natural) teeth:

> "*Your teeth*, *they* (. . .) *help create your facial expression*, *that way they also add to your identity*. *I think it plays a role in how people see you*, *the way you look and the way your mouth looks play a role in that*. *I recently came across a former acquaintance*. *He had this crooked mouth and I only saw a few teeth*. *Well that makes someone look so*…. *I wanted to say* '*decayed*' *but that sounds disrespectful*. *But old*, *and*

> *uncared for*. (. . .). *I would like to keep my own teeth*. (...) *I think people judge me differently when my teeth change*, *the first impression is different*." (woman, 69, slightly frail).

The idea that natural teeth contributed to personal identity was shared among several participants across all frailty categories and was reflected in comments like: "*you become a different person with artificial teeth*". Although most people wanted their teeth to look well cared for, they were only prepared to have major imperfections, like missing or rotten teeth in visible positions, restored. Minor imperfections, like skewed or stained or yellow teeth, did not bother them enough to undertake action, mostly because they set their standards based on what they saw around them in their peer group or what they thought would be normal for their age.

Comfort

'Comfort' addressed in large part the psychological aspects of impairment, including enjoyment of food and absence of embarrassment, and was related closely to function. Most participants who thought that natural teeth contributed functionally to QoL, also thought that natural teeth contributed to a higher level of comfort through absence of worries about eating, speaking, loose teeth, ill-fitting dentures or dental appearance. Being able to enjoy food and the taste of food were the items that were often mentioned in relation to advantages of having natural teeth:

> "*If I would not have my own teeth*, *that would be a big loss*. *I know people who say*: *I don't eat this fruit because I can't have those little seeds underneath my dentures*. (...) *And like in restaurants*, *I would hate it if I would have to skip menu's or dishes because of fear of dentures falling out or food sticking to those fake teeth or whatever* (. . .). *It would take away the joy of eating out*." (man slightly frail, 72).

Social activities were sometimes avoided by people with uncomfortable dentures. Problems with speaking or communication caused by impaired oral health were mentioned only on the context of imagining from observing other denture-wearers.

Absence of pain and irritation was crucial to good QoL for people across all frailty categories. A small number of participants reported that they were experiencing orofacial problems during the interview, mostly from ill-fitting removable dentures.

Few participants felt that maintaining natural teeth compared to dentures could require more time and effort. Almost everyone was bothered by attending a dentist, although only a few participants mentioned fear or particularly bad experiences, and one participant stopped seeing a dentist for fear caused by bad experiences. Fear of loss of decorum was associated with removable dentures:

> "*I had this aunt*, *if she had a meal then she dug up a big white handkerchief from her handbag and once she started eating*, *then she wrapped her dentures in it*. *That's something I hope to never experience myself*. *How awful*, *when you're somewhere without your teeth*."
> (woman, 72, moderately frail).

On the contrary, a few participants who were content with their partial removable dentures, explained that if their natural teeth caused problems, they would have to be removed.

Adaptation and coping

Participants generally experienced deteriorating teeth as something that inevitably happens with age, and so they reasoned that "*if you can't change the situation*, *you should accept it and cope with it*." Participants who were very frail who felt that their oral health was poor seemed particularly resigned in this way:

> "*It is easy for me to accept that my teeth are getting worse*. *I don't really mind*. *It is something you can't change anyway*. (. . .) *Everything gets worse with age*" (*woman*, *85*, *severely frail*).

Several 'younger' or slightly frail participants remarked that they did mind losing their teeth now, but that they expected to accept it with more ease with increasing frailty:

> "*I am still relatively young now*, *but when I would be 85 or 90*, *I expect I would have a different view*, *depending on my general health*. *If my health would not further deteriorate*, *I would still think the same about my mouth*, *but I expect that I would care less if I would be demented or have other ailments that affect my life and that I cannot control*. *It really depends on which diseases I would have and how bad they would be*." (man, 69, slightly frail).

Participants who did not mind losing their teeth, seemed also resigned to a deterioration in their general health. The adaptive strategy used was to anticipate oral health decline through lowering expectations, to compare themselves to others who had lost their teeth, or to judge the importance of teeth in relation to other life and health events:

> "*Throughout the years*, *you don't know if your teeth are still important to you or not*.(..) *So many things play a role*, *like with my health in general*. *I can hardly walk anymore*, *I had to move to this home*, *so many things changed*. (..) *I suppose it made me less concerned about my teeth*." (woman, 84, moderately frail).

Discussion

This study revealed how having, caring for and having preserved natural teeth in general improved the quality of life of frail older people through a sense of achievement, pride, a sense of control, intactness, oral function,

comfort and appearance. We identified a not previously documented response, especially by severely frail people with chronic pain, that involved clinging to an intact body part (natural teeth) as a means to preserve self-worth, in particular through pride, a sense of control, and a sense of intactness. This is also the first study to indicate how particular frailty aspects (chronic pain and impaired fine motor skills) and the degree of frailty modify the relation between QoL and having natural teeth.

Both quantitative studies [25,26,30,42,43] and qualitative studies [28,29] have identified the positive contribution of natural teeth to QoL, but only MacEntee and his collaborators [28] have addressed this contribution in some detail. Their observations largely correspond with ours, but, as natural teeth were not the focus of their research, they did not provide a comprehensive analytical context and identify specific factors that reflect the value of having natural teeth, or identify the positive effect of natural teeth on self-worth and personal identity, as we did.

Strengths and limitations of the study

One of the strengths of our study is that its design enabled differentiation between participants with different levels and characteristics of frailty. Hence we were able to compare responses between people of different degrees of frailty and with different frailty characteristics, even though comparisons based on frailty characteristics did not reveal obvious differences other than those related to chronic pain and impaired fine motor skills.

By focusing on natural teeth and its contribution to QoL in 38 lengthy interviews, we were able to cover the subject in more depth than previous studies that focused on oral health in general. Moreover, by explicitly asking what constituted QoL for the respondent before asking about the contribution of natural teeth to QoL, we could explore the value of natural teeth to QoL domains that were deemed important by the participant.

Apart from chronic pain and loss of fine motor skills, loss of cognitive function is probably another strong, frailty-related, influence on oral health related QoL [4], but our interviews were limited to elders who were cognitively alert. Nor did we include edentulous people because we were primarily interested in the value of natural teeth to QoL of frail elders. However, older people without natural teeth could add insight to the value of having natural teeth by comparing their experiences before and after tooth loss, an experience that is generally but not always unpleasant [28,31,33].

We looked at coping and adaptation, which we expected to be the most relevant personal aspects in relation to our study aims, but not at other personal traits like neuroticism, extraversion, and openness, which may [44] or may not [45] influence dental perceptions. Likewise, in our analysis, we did not account for socioeconomic status (SES), even though there is evidence that higher SES has a positive influence on OHRQoL [46,47].

The influence of cultural background could not be comprehensively evaluated, since our study included only two people from non-European heritage, which was due to the lack of non-European dentulous elderly who live in RACFs or frequent daycare centers in East-Netherlands.

Meaning of the study: possible explanations and implications for research

The impact of achievement and pride, intactness and sense of control in relation to having natural teeth seemed to be the most obvious for severely frail, institutionalized people. This impact can be understood with help of social comparison theory [48] and a theoretical model from educational psychology: The internal/ external frame of reference model [49]. According to this model, students base their self concepts on two simultaneous sets of comparisons. The internal comparison (or “frame of reference”)

includes an individual student's appraisal of competence in one academic area compared to his or her competence in other academic areas. The external comparison is the student's appraisal of his or her competence in that academic area relative to the perceived ability of peers, following social comparison theory.

Likewise, our participants, by attributing value to having natural teeth, compared their oral status both externally with their peers and internally to other health areas e.g. their own mental health or motor abilities. For the most severely frail dentulous elderly, both external and internal comparisons are likely to contribute more to a concept of self in a positive way [50], than for slightly frail or non-frail dentulous elderly. The severely frail, especially if they are institutionalized, are more often surrounded by other severely frail people, who are more likely to be toothless than less frail or non-frail elders [51]. Hence, when severely frail dentulous elders compare themselves to their, mostly edentulous, peers (external comparison), they feel more special since they are one of the very few who still have natural teeth. Making an internal comparison, people value their dental status in comparison to other health areas. Dentulous frail older people realize that their teeth have remained in relatively good condition while other parts of their body have declined. When the decline in other health areas is more severe, the contrast with healthy teeth is even greater, and teeth can contribute even more significantly to self-worth. In contrast, the experiences of increasing frailty can help prepare people to cope and accept tooth loss, which corresponds with current beliefs about coping resources and declining health [17,52].

This study revealed the contribution of having natural teeth to a positive body-image, not only through dental appearance, but also through intactness and normal functioning, all of which aspects are integrated in the body-image concept as described by Carver *et.al* [53]. Donnelly *et.al*. [54] indicated how oral impairments could negatively affect

the body image of elderly people and consequently decrease self-esteem. She warned that elderly, living in a society where the emphasis is on youth and beauty, may become increasingly concerned about their dental appearance and feel inadequate when they do not have white and straight teeth. Most of our participants, however, did not mind that their teeth were a bit yellow and misaligned. They were more concerned about keeping their own teeth, since artificial teeth made them 'feel like a different person.'

This association between natural teeth and identity (of which body image is a 'central aspect' [55]) at old age, may become more important to OHRQoL as people age and become more frail, than the mere aesthetic aspects of teeth. Most consulted literature indeed supports the idea of decreasing emphasis on physical attractiveness in relation to QoL as people age [56-59], while the experience of bodily decline appears to "urge old people to redefine their identity" [60]. However, further research in the area of oral health is required to test our hypothesis.

The way natural teeth can contribute to a more positive body image and self-worth, cannot be measured by existing OHRQoL instruments. More in general, and to our surprise, body image assessment has not been integrated into the oral health related QoL literature, and has only recently become a topic in health related QoL literature [61-64], despite consistent observations that changes in physical appearance, function, and body integrity are crucial to the experience of health and illness [65]. It may therefore be useful, when researching the OHRQoL of frail elderly, to supplement commonly used OHRQoL instruments like OHIP and GOHAI with questions that target the influence of oral health on body-image and self-worth, e.g. "Do you think that your teeth positively contribute to (a) how others perceive you; (b) how you perceive yourself."

Implications for the health sector, health care staff and the dental profession

We found that the severely frail people were less able and less prepared to take good care of their teeth, despite the value they attributed to having natural teeth. There seems to be a turning point where frail people abandon oral care, and our participants indicated that this occurred when they experienced other more disturbing discomforts or pain. At the same time, our results show that even the most severely frail generally wish to keep their natural teeth and benefit from keeping them.

Both the health care and public health sector should become aware of the QoL benefits of preservation of natural teeth even for severely frail people. We recommend the dental profession and health care staff to adopt a patient-centered approach through identifying individual oral health needs and wishes of frail dentulous elderly and translating these into a tailor made care plan. In identifying those needs, health care staff needs to be alert to care behavior and the general oral condition. Several of our participants had unclean teeth and simply wanted to be reminded about or help with brushing their teeth or with dental visits, so enhancing their QoL may not require that much effort.

However, the required effort needs to be facilitated by the health care and public health sector through allocation of appropriate resources. Only then, the type of requested oral health care, including assistance with daily oral care and arrangement of dental visits, can be better geared to preserve teeth and sustain QoL of frail older people, than is currently the case.

Conclusions

Participants generally agreed that having, caring for and having preserved natural teeth contributed to their QoL through a sense of achievement, pride, sense of control, intactness, better oral function, more comfort and

nicer appearance. The impact of achievement and pride, intactness and sense of control in relation to having natural teeth seemed to be the most obvious for severely frail, institutionalized people. In the course of increasing frailty, preservation of teeth can help to enhance a positive body image and self-worth, and positively influence QoL.

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Chapter 3

The impact of frailty on oral care behavior of older people: A qualitative study

This chapter is an edited version of the published article: The impact of frailty on oral care behavior of older people. A qualitative study. Dominique Niesten, Krista van Mourik and Wil van der Sanden. *BMC Oral Health* 2013,13:61

Abstract

Background: Frailty has been demonstrated to negatively influence dental service-use and oral self-care behavior of older people. The aim of this study was to explore how the type and level of frailty affect the dental service-use and oral self-care behavior of frail older people.

Methods: We conducted a qualitative study through 51 open interviews with elders of varying frailty in the East-Netherlands, and used a thematic analysis to code transcripts, discussions and reviews of the attributes and meaning of the themes to the point of consensus among the researchers.

Results: Three major themes and five sub-themes emerged from our analyses. The major themes indicate that frail elders: A) favor long-established oral hygiene routines to sustain a sense of self-worth; B) discontinue oral hygiene routines when burdened by severe health complaints, in particular chronic pain, low morale and low energy; and C) experience psychological and social barriers to oral health care when institutionalized. The subthemes associated with the discontinuation of oral care suggest that the elders accept more oral pain or discomfort because they: B1) lack belief in the results of dental visits and tooth cleaning; B2) trivialize oral health and oral care in the general context of their impaired health and old age; and B3) consciously use their sparse energy for priorities other than oral healthcare. Institutionalized elderly often discontinue oral care because of C1) disorientation; and C2) inconveniencing social supports.

Conclusion: The level and type of frailty influences people's perspectives on oral health and related behaviors. Frail elders associate oral hygiene with self-worth, but readily abandon visits to a dentist unless they feel that a dentist can relieve specific problems. When interpreted according to the Motivational Theory of Life Span Development, discontinuation of oral care by frail elderly could be viewed as a manifestation of adaptive development. Simple measures aimed at recognizing indicators for poor oral care behavior, and providing appropriate information and support, are discussed.

Introduction

There is abundant evidence of a discrepancy between perceived oral treatment need and dental service-use by older people, a discrepancy that has persisted for more than 35 years [1-6]. Studies have indicated that, of a group of non-institutionalized elderly people with clinically assessed or normative oral treatment needs, about half perceived the need and about one quarter sought treatment [4,7]. Recent studies among elderly residents in Dutch and Italian nursing homes showed even larger differences between normative and self-perceived needs [8,9]. Apparently, large discrepancies exist between self-perceived and normative treatment need, and between self-perceived treatment need and service-use.

Frailty, as a "dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social)" [10], is likely to contribute to these discrepancies by negatively affecting both dental service-use and oral hygiene-related behaviors [11]. However, despite extensive research on barriers to dental service-use [7,12-17] and oral hygiene-related behavior [18-21] in which barriers have been associated with impaired mobility, impaired activities of daily living, low energy, depression, and lack of social support, it remains unclear how frailty in its many forms influences the oral care of older people. For example, it is not clear whether service-use and tooth brushing are disturbed more by impaired mobility, dexterity, or low morale, or, as some [22,23] suggest, by a lack of time and energy caused by more pressing general health problems.

Nor do we know what motivates frail people to apply oral care despite physical and cognitive impairments, or why there are discrepancies between perceived treatment need and service-use. This knowledge should help to make evidence-based decisions about the allocation of resources aimed at improving the oral health related quality of life of people who are affected by frailty. This study aims to explain how frailty influences dental service-use and oral self-care by older people.

Methods

Open-ended or in-depth interviews [24] were conducted with a group of elderly participants selected purposively for maximum variation in response to the topic guide [25]. This strategy allowed us to identify common patterns in responses across people with maximum variation in variables that are known to influence the oral health behavior of the target group: age [22,26-28], gender [26,27], dental status [15,22,28,29], institutionalization [13,14] and type and intensity of care they receive as a measure for frailty [15,16,20,21,30,31].

Setting and Participants

The selection of recruits followed the procedure described in Chapter 2, with the only difference that in this study, both dentulous and edentulous people were included. According to the care-managers, most recruits consented to participate. Reasons for non-participation were not collected. All participants were 65 years or older and gave informed consent in writing with the approval of the Medical Ethics Committee (CMO) of the Radboud University Nijmegen Medical Center Nijmegen (CMO ref. 2009/153).

Data collection and analysis

Two trained interviewers (DN, KM) conducted the open-ended interviews with 51 participants (Table 1) between 2009 and 2012. We used an interview guide to focus attention on: 1) self-reported oral and general health; 2) oral self-care; and 3) use of dental services. We made observational notes to record events that might have influenced our interpretation of the interviews. In most cases, and in every case where we received any unclear or contradictory information from the participant, we contacted care-managers after the interview, either in person or by telephone, in order to briefly discuss our interpretation of the information.

Table 1. Participant characteristics

Participant Characteristics	Number
Gender	
Female	35
Male	16
Age	
65-80 yr	24
>80 yr	27
*Care-level package**	
CLP1	14
CLP2-3	17
CLP4-6	20
Dental status	
natural teeth only	15
nat. teeth and partial dentures	12
nat. teeth and full upper dentures	12
full upper and lower dentures	12
Institutionalized	
Yes	28
No	23

*Zorgzwaartepakketten (care level package CLP). Source: V&V Enschede 2010 PJ/10/1657/imz.

Interviews occurred in a quiet room within each facility or centre or in the participant's private room or home. Data were collected on the age, chronic disorders, use of dental prostheses (all self reported), and CLP (care-level packages (CLP); in Dutch: 'Zorgzwaartepakketten') as registered in the medical record of each participant (Table 2). Substitutes for missing CLP scores were derived through consultation with the care-manager and based on the table below. All interviews were audio-taped, transcribed verbatim, and the identity of each participant was masked to maintain anonymity.

In order to identify the specific themes relating to the care behavior of the participant [24] (p.67), DN and KM first applied line-by-line coding of each transcript. We then discussed and reviewed the attributes and meanings of the codes until consensus was reached. This way, a coding frame developed. The coding process and analysis was supported by a computer program (MaxQDA 2010; www.MaxQDA.com) which also facilitated (semi-)quantification of codes and emerging themes during the analysis. A third researcher (WS) checked the reliability of the attribution of codes in five randomly selected interviews. DN

and KM grouped coded segments with related content into code groups. We then formulated an initial set of themes based on the underlying meaning of grouped coded segments. Themes were repeatedly compared with the data following a method of 'constant comparison' [24] (p.71). We applied this method after every two or three interviews in order for emergent themes to b-e verified and explored in interviews that followed. The discussion and subsequent refining of themes among all authors went on until we reached consensus on a definite set of themes. The analysis included the identification of the specific influence of different levels of frailty (CLP 1–6) on care behavior both within and between transcripts by the references to frailty or related conditions, such as impairments or disabilities. In order to increase comprehensibility in the reporting phase, we hereby distinguished between slight frailty (CLP 1), moderate frailty (CLP 2 and 3), and severe frailty (CLP 4 through 6).

Table 2. Type and intensity of care according to Care Level Package (CLP)

	Assistance		Care			Medical care	Behavioural disorders	Care indication Hours/wk
CLP	social coping	psychosocial functioning	personal care	mobility	motoric functioning			
1	+	0	+	+	0	0	0	3-5
2	+++	+	++	+	+	+	0	5,5-7,5
3	++++	++	++++	+++	++	+	0	9,5-11,5
4	++++	+++	++	+	+	+	+	11-13,5
5	+++++	++++	++++	++++	++	+	+	16,5-20
6	++++	+++	+++++	+++++	+++	++	0	16,5-20

0 means that no care is needed in the referred category. ++ = coaching needed; ++++ = support needed; ++++++ = staff taking over. *Zorgzwaartepakketten (care level package). Source: V&V Enschede 2010 PJ/10/1657/imz.

Reflexivity of the researchers

Insights from various academic and professional backgrounds influenced the data analysis. The researchers added expertise in and knowledge of public oral health care and philosophy (DN), health sociology and medical anthropology (KM), dentistry and dental care (WS), and qualitative methodology (DN and KM) to the analysis. The only dental professional of the team did not conduct the

interviews in order to reduce the chance of participants feeling restricted in their responses.

During the study design and in the analysis phase, we repeatedly consulted geriatric dentists and geriatric nurses to help us to bring up relevant issues during the interviews, and to create more contextual background to understand the participant's information.

Qualitative rigor

Several techniques helped to ensure the trustworthiness and credibility of our analysis [32]. Firstly, we combined or triangulated information from three sources: interviews; observational notes; and the opinions of care-managers. Secondly, the research team brought three separate professional backgrounds to the analysis. Thirdly, the interviewers carried out member checks during the interviews, which involved restating or summarizing information and then asking the participants to determine the accuracy. Lastly, we offer direct quotes from the transcripts to support our thematic interpretations. We stopped interviewing when no new themes or subthemes emerged (theme saturation) [33].

Results

The views and experiences on oral health behaviors of most slightly frail (CLP 1) and some of the moderately frail (CLP 2 and 3) participants were very similar. They said that their oral hygiene routines had not altered much since their youth or early adulthood. All brushed their teeth daily and nearly everyone visited a dentist regularly.

The effects of frailty on oral care behavior only clearly manifested themselves for about half of the moderately frail (CLP 2–3) and most of the severely frail (CLP 4–6) people. The themes presented below are therefore predominantly, but not exclusively, based on their accounts. Apart from frailty levels and frailty factors, we paid attention to the factors age, gender, dental status and being institutionalized in case these appeared to influence the

theme.

We identified three main themes and six subthemes relating to oral care behaviors of frail people. Quotes that best illustrate these themes are provided in Tables 3, 4 and 5.

Theme A: oral hygiene routines sustain a sense of self worth

There was a strong desire to remain the same person as before the onset of health decline, if not through maintaining the same level of oral health, then at least through adherence to the same daily oral hygiene routines. The importance of adhering to routines seemed even stronger for people who felt quite weak; it helped them to sustain their sense of autonomy and self-control, and hence self-worth. Some severely frail participants continued to brush their teeth daily, despite physical difficulties (Table 3, qA1), in an attempt, especially among 'younger' (65 – 80 y.o.) women, to appear well-groomed.

Table 3. Theme A and supporting quotations

Theme A: Adhering to routines in order to sustain a sense of self worth	
A1	A while ago, I was in hospital for a week where they gave me a special bowl to brush my teeth in. I find that awful, very awful. But there's no way around it when you can't stand up. (…) I still think I should not skip brushing. (…) I wish to feel clean. (woman, 70, severely frail, severe Parkinson).
A2	I just wanted to feel normal again. When you do your daily routines, combing your hair, brushing your teeth, just like you always do, it feels as if you're not that ill. (man, 75, talking about his recent stay at the intensive care unit after acute renal failure).
A3	I wish to be cared for, I don't won't to lie here as a pile of old dirt, that goes for the mouth, for everything. (woman, 86, severely frail).
A4	If a nurse talks to me and brushes my teeth and then she says, well that's nice and fresh like this, by saying so she lets me know that I still count as a human being. (woman, 80, slightly frail).
A5	You owe it to yourself to maintain a healthy mouth (…) I live healthily, I hardly ever take sweets and I brush my teeth every night. (woman, 94, moderately frail)
A6	I like to care for my teeth (….) I like to be able to care for my teeth. It is so important that you don't neglect your personal care (…) they have told me that I have always looked so well after my body and my teeth (…) that makes me proud. (woman, 70, severely frail, severe Parkinson).
A7	In that case (if she would not brush and her teeth would be visibly unclean) I'm quite sure that people would think 'can't that person brush her own teeth anymore'? (woman, 78, moderately frail).
A8	I thought, all those nurses, they get quite close to you. (…) I would really dislike it if they would see me as mister rotting. (…) as someone who is too slack to prevent the decay that after all he can do something about. (man, 75, severely frail, talking about his recent stay in hospital).

One man in an intensive care unit explained how he brushed his teeth in order

to feel 'normal' as soon as he was well enough to get out of bed (qA2). This also applied to severely frail people who needed help with their daily oral routines, and who wanted to maintain their dignity by being and feeling well cared for (qA3). Support and attention from staff was not only expected to increase oral hygiene; it also made people feel worthy of care "I still count" (qA4). Those who were less dependent felt that mouth-care demonstrated self-control (qA5), and they associated neglect of their mouth with human decay and loss of dignity. Only a minority seemed unconcerned about discontinuing oral hygiene routines and losing control associated with oral self-care. These were mostly males, edentates, people who had never cared much about their oral health and a few severely frail people distressed by pain.

Maintenance of formerly established oral hygiene-related behavior contributed to self-worth not only through the concept of self in relation to "I" (how I see myself) (qA2 – A4, A6), but also through the concept of self in relation to others (how others see me) (qA7, A8). In the latter case, the contribution of oral hygiene-related behavior to self-worth was related to the extent of social involvement of people and the extent to which they valued this social involvement. People who enjoyed frequent visits from friends or relatives or who actively participated in social activities, generally put more emphasis on the social aspect of a clean mouth, than did those who were less socially active.

For only two people did use of dental services also contribute to their perception of themselves as normal functioning human beings, albeit to a lesser extent than tooth brushing did. With increasing frailty people abandoned their dental visits much sooner than their daily tooth brushing routines.

Theme B: lack of motivation: the benefits of dental visits or daily tooth cleaning are not worth the effort

The majority of wearers of complete (full) and removable partial dentures and the majority of the frailest, institutionalized participants, did not see a dentist anymore. Most said that they did not feel they needed to go, or that it required

too much effort with no obvious benefit, which was remarkable since about half of the participants who did not see a dentist anymore complained about uncomfortable and loose dentures, loose teeth or painful spots.

Table 4. Theme B and supporting quotations

Theme B: Lack of motivation: the benefits of dental visits or daily tooth cleaning are not worth the effort	
Subtheme: lack of belief in results	
B1	It's not that I don't want to go, but whom should I see? From what I have come across, it is only misery. (man, 93, full dentures, severely frail).
B2	When I take my dentures out, it feels freed. But I have to wear them, so… You think what could be done about it, I understand, but if I would have believed that a dentist could help me, I would have gone there a long time ago. But I know that it wouldn't help. (woman,86, full dentures, slightly frail).
B3	I've got this feeling that my lower jaw is shrinking a lot. There's hardly anything left there. But that's a family thing, my mum had that too. (woman, 85, full dentures, moderately frail).
B4	They (dentures) have not been sitting well from the beginning.But I've always thought that it was because of this fungal infection, I had in my gullet. (..) That that infection has moved up to my mouth. (…) Cause my mum had the same, her mouth was always sore. (…) And her gums were sore too. And then she was rubbing like this. (…) I have determined for myself that it really is that fungal infection. (…). And I won't go to the dentist, because that is no use, they cannot fix it. (woman,86, full dentures, slightly frail).
B5	I don't go anymore. He (a dentist) can't do anything for me, can he? (…) Last time I went was 10 years ago, and ever since I have not had any complaints, so why should I go? (woman, 85, dentate, moderately frail).
B6	Well I have tried to clean them (dentures) with a brush, but they weren't that dirty, and they didn't get that clean either (…) well, no moss grows on them (dentures), what else should you care about? (man, 93, full dentures, severely frail).
Subtheme: Reduced importance of oral health and oral care	
B7	I simply cannot brush my teeth properly anymore. (…) But I don't mind having to take dentures. (…) My health is more important than my teeth now. (man, 80, severe Parkinson, severely frail).
B8	When you can't do anything anymore, then you don't wish to do anything anymore, then you can't be bothered about anything. (woman, 85, severely frail).
B9	My teeth don't interest me. Because I am depressed. (…) I only rinse them (dentures) when something gets underneath, and that's it. (…) I don't know if a dentist could help me, I don't care. (woman, 73, moderately frail).
B10	I can't get them 100% clean, not even with an electric toothbrush (…) It is too hard to reach them (…) I've tried, but it didn't work, and now it doesn't bother me anymore. (…) I don't mind losing my teeth. (man, 80, severely frail).
B11	I wouldn't (see a dentist), not unless I would have serious toothache. Life won't last that long anymore when you're so old as I am. (…) My teeth will keep, I think. (woman, 85, severely frail).
B12	I'm only bothered with having a fresh feel in my mouth now (…) when you've kept your teeth this long like me, they will survive. (woman, 84, moderately frail).
B13	I would not go to the dentist (in order to replace bad teeth). (…). If I cannot bite anymore I will eat porridge. (woman, 93, severely frail).
Subtheme: Conscious choice to preserve energy for other goals	
B14	I don't see a dentist anymore. I don't feel like it. I rather preserve my energy for other things. (…) But if I would have pain, I would go again. I wouldn't go on with a painful mouth. (woman, 77, severe arthritis, severely frail).
B15	When I can achieve, with only a small effort, that my mouth remains fresh and a bit healthy, then I don't mind doing it, but if it takes a big effort, then not, which is why I don't see a dentist anymore. (woman, 93, severely frail).
B16	And in the past I would clean my dentures after a meal, but, and that is laziness, I openly admit it, I don't do that anymore. (…) After all it takes an effort, and I have to divide my energy sensibly. I could go walk back and forth to the bathroom, but I rather be knitting something, or do something else. (woman, 86, severely frail).
B17	I don't wish to look for another dentist, because that requires a lot of you. When you get older and weaker (…) you can't work up the effort. I could do it when I was younger, but now, look I don't cycle anymore. I am just slower (…). It really is not important enough. (…) And now I need to look after my husband (a Parkinson patient), and I have to save all my time and effort for that. (woman, 80, slightly frail).

A small minority of people, all severely frail with impaired mobility or dexterity or with low energy, also reduced their tooth brushing frequency or stopped cleaning their teeth altogether. We identified three underlying subthemes that explained reduced motivation.

Lack of belief in results

Most complete denture-wearers had stopped making dental visits, either because of bad experiences with dentists and denture-makers, or because they had not been to a dentist for many (often 20 – 30) years and could not imagine how a dentist could help them (Table 4, qB1,B2). The general conviction among denture-wearers was that dentures are unavoidably uncomfortable, and complicated by old age, diseases or even poor genes (qB3, B4), and that relief was more easily obtained by simply not wearing the lower denture than by visiting a dentist. A minority of dentates had stopped making dental visits (qB5) mostly because they did not perceive any benefits of these visits other than pain relief. The perception that dentists are unhelpful might also have been a cover for the belief that visiting a dentist needed too much effort, which some felt was shameful to admit. With respect to tooth cleaning, a few participants mentioned that they lacked motivation because they did not believe that they could effectively clean their teeth (qB6, B9, B10). This lack of self efficacy was a result of physical impairments and was confirmed by unsatisfying results of cleaning efforts.

Reduced importance of oral health and oral care

Awareness of declining health, especially in the very old, had two effects on attitude towards oral health. Interest in preventing oral disease was lost as frailty increased (qB7). Participants with low morale or chronic pain or severe impairments that absorbed their vitality, lost interest in oral care (qB7-B9). Others with poor dexterity resulting from Parkinson's disease,

rheumatoid arthritis or other disabling disorders, trivialized oral health when they realized that they could not clean their teeth effectively (qB9, B10).

Health decline in old age also had another effect on attitudes towards oral health and oral health behavior: People realized that since death was close, the teeth that they had would probably last without professional care or major discomfort (qB11 - B13). Thus, even if dentists were willing to make home-visits, some participants said that they would refuse professional care unless the mouth or tooth pain would become unbearable.

Conscious choice to preserve energy for other goals

When people indicated that they did not brush their teeth as often as before or had stopped seeing a dentist, the underlying reason was often a conscious decision to use their scarce energy in other ways. The presumed investment of energy into dental visits, a higher brushing frequency, or flossing, did not weigh up against the perceived benefits, unless the perceived benefit was relief of serious pain or discomfort (qB14-B16).

Severely frail people with low energy levels due to mental or physical impairments, were well aware that they had to spread their energy over actions that they considered important or worthwhile. While for most, daily tooth brushing was still important enough to do, seeing a dentist was not (qB14) or required an amount of effort that could be better spent in other ways (qB17), a view that was even shared by some slightly frail people.

For most participants the perceived benefits of tooth brushing (mainly, having fresh breath and feeling clean and well-groomed) outweighed the negative consequences of having to make the effort, or remind a nurse to do it (qB15). However, this balance seemed to go in the opposite direction for a few severely frail participants, some of them bedridden, who chose to diminish the frequency of their oral hygiene routines (qB16).

Theme C: Structural barriers: I'd like to, but I can't

Besides the people who lacked motivation to see a dentist or maintain their old tooth brushing behavior, there were also people who encountered external barriers to dental visits or oral hygiene practices as a result of frailty-related limitations. The main factors identified as direct disablers of oral care behavior, were diminished mobility and dexterity, disorientation, failing memory and dependence on, or lack of support from others, all of which have been documented before.

However, it was noticed that, in contrast to psychological and social barriers, physical barriers, like being wheelchair-bound were often not in themselves sufficient motivators for giving up or altering oral care behavior. Rather, these barriers accumulated with other factors and then made the balance of required efforts versus perceived benefits tip over to the 'too much effort' side, especially in severely frail people.

It was noticed that in particular the effect of psychological and social factors seemed to be reinforced by institutionalization, and two related themes emerged.

Disorientation: I don't know how it works here

Being institutionalized constituted a major change in oral health behavior for many severely and moderately frail people. After arriving at a home, people often stopped seeing a dentist. This was either because their old dentist was too far away, or because they had not been informed if the home had its own dentist or not and hence did not know if they should keep seeing their old dentist or not, or because they had been informed about the home's dentist but not about how to arrange dental visits (Table 5, qC1).

Table 5. Theme C and supporting quotations

Theme C: Structural barriers: I'd like to, but I can't	
Subtheme: Disorientation: I don't know how it works here	
C1	Since I live here, I don't always get the right care. Because I don't know how it works when I need care here, if I should go back to see my old dentist or if they (staff) arrange someone. I wouldn't know. (woman, 86, recently institutionalized, slightly frail).
C2	I wouldn't mind seeing a dentist, but I don't know anyone here. I don't know who would be good. (…) Everything is so distressing here. (woman, 79, moderately frail).
C3	I would have to look up where to go to. I am not at home anymore. And I don't have all the addresses anymore. So to find all that out, that is an enormous….But I should do it. I should look up where my own dentist is. And then I should go. It has been too long ago since I went there. (woman, 93, severely frail).
C4	I have to brush regularly. And, you should write this down, that does not happen here. They forget to help remind me. You have to do it yourself (…) and then I lie on my bed and I think, oh my God, I did not brush my teeth. And I cannot walk by myself, I need someone to bring me to the bathroom (…) They don't help me enough. I am forgetful now, and they don't remind me.(…) I have looked after my teeth my whole life, and now they let it get in a mess. (woman, 93, severely frail).
C5	It is a bit difficult with my hands (…) and to reach the wash basin. (…) (interviewer: why haven't you asked the nurses to help you?). I didn't think about it, didn't know I could do that. (man, 65, spastic, wheel chaired, severely frail).
Subtheme: Inconveniencing social support: getting (the right) help is hard	
C6	I do want to have it fixed. (…) but I cannot burden my daughter to take me to the dentist as well. She has had enough on her plate. (interviewer: and have you considered asking your other children?) Well I have asked it enough. I cannot go on insisting. "Mum, stop nagging," they say to me. (woman, 83, severely frail).
C7	I would only go now if I would have pain. And then I would ask my daughter to bring me to the dentist. (…) I would only go if she can make it, because she's busy herself. (woman, 97, severely frail).
C8	I still live independently and I have to bother people with my requests so often, and I have to ask so many people to do something for me, and I don't like that. (woman 80, slightly frail).
C9	The whole inside hurts because of my lower dentures. And I thought, I should go the dentist, but well, I don't have a husband no longer, and that means I would have to go there myself. (…) So I haven't gone yet. (woman, 87, slightly frail).
C10	I think that a nurse does not like to brush my teeth. A nurse is not really paid to do it, has not been trained to do it (…) that makes it hard to accept help, the thought that people do not like to help you brush, it makes you feel so dependent. (woman, 80, slightly frail).

A lot of people, even after two or more years, were still getting used to the new environment and routines in their care homes. Assessing the dental care situation, let alone organizing a visit, did not have their attention or had low priority. There was a plain element of distress in most accounts (qC2), because people thought that they ought to see a dentist but felt that they were not up to the task of either arranging a visit or of getting there (qC3).

Disorientation, albeit to a lesser extent and mostly in people who were mentally frail, also played a role in daily hygiene routines of institutionalized participants (qC4).

Some disabled people had reluctantly given up tooth- brushing because they could not do it themselves and had not considered asking

help from a nurse, because they had 'never thought about it' and were clearly unaware of the possibility of getting assistance from staff (qC5).

Inconveniencing social support: getting (the right) help is hard

Although most people were aware that they could ask for help to arrange and make dental visits, and although almost everyone could name someone that they could ask for help, they were very careful not to overburden their relations (qC6). In most cases there was a long list of actions that required help from others, and making a dental visit was often not among the most urgent ones. For most people, the only reason that justified asking for help from others, was oral pain (qC7). Barriers related to social support also played a role for a few non-institutionalized people who lived alone (qC8, C9).

Complaints about the support they received from nurses were not limited to reminders to brush or clean dentures (qC4). Nurses, it was said, did not put the brush or the dentures back in the same place every time, they were too rushed, and did not always clean or rinse dentures properly, so that they remained dirty or tasted of soap.

Almost all participants wished to keep their independence and insisted on brushing their teeth themselves for as long as their general health allowed them to do so. People with disabling disorders like impaired dexterity or vision, incessantly had to weigh up their need for properly brushed teeth against their loss of independence. The thought of losing independence was clearly mitigated by the attitude of the caregiver, who, according to several participants, could make the difference between people's asking for help and accepting it or people neglecting their oral care (qC10).

Discussion

New insights and possible explanations

This is the first study to our knowledge that provides in-depth insight into the pathways through which manifestations of frailty affect oral care behavior,

particularly with regard to continuation or cessation of oral care behavior. We identified several established frailty factors [34] that influenced oral care behavior in different ways: chronic pain, impaired mobility, impaired dexterity, low energy (physical frailty), disorientation, bad memory, low morale (psychological frailty), and lack of support (social frailty).

Chronic pain, low energy and low morale mainly affected oral care behavior through devaluation of oral health importance (attitudes) and by reducing motivation. Physical constraints reduced self-efficacy beliefs with regard to oral hygiene practices, while bad past experiences, often in combination with reduced motivation, affected outcome expectations with regard to dental visits, especially for denture wearers. Impaired mobility and dexterity, disorientation, failing memory and lack of social support constituted structural barriers to oral care behavior that could only be reduced by others, and institutionalization seemed to increase the effects of psychological and social frailty factors on oral care behavior.

Identified frailty factors, often in combination with a lack of belief that a dentist could improve their oral health, together with increasing frailty and/or institutionalization caused most people to decrease or end their dental service use, but not abandon daily hygiene routines. This was because tooth brushing, in contrast to dental check-up visits, was seen as a necessary and manageable effort for maintaining good oral health, and because adhering to formerly established tooth brushing routines helped frail people feel 'normal' and hence maintain self-worth and dignity. While the role of self-worth, in particular autonomy, in adherence to general health care routines for institutionalized elderly has been documented [35,36], as has the role of self-worth in having natural teeth in old age [37], no literature, to our knowledge, explicitly links self-worth and oral hygiene-related behavior for this group.

Character traits, particularly psychosocial constructs like self-efficacy [38], locus of control [39], optimism [40], sense of coherence [41], hostility [42], coping and adaptation [43], and resilience [44], have a proven influence on oral hygiene-related behavior. Our interviews seemed to support the already large body of evidence implying that self-efficacy has a vital influence on oral care

behavior [18,19,38,45-49]. We also found some support for the view that people with a high internal locus of control (interpreting events as being dependent on his/her own behavior) would less readily give up their dental check-up visits and tooth brushing than people with external locus of control, while people who seemed good at adapting to their impaired health would give up dental check-up visits easily or not mind if they could not clean their teeth properly.

This study shows that commonly recognized barriers to dental service-use by elderly, 'availability', 'accessibility', 'cost', 'dependence on others' and, in some cases, even 'perceived oral problems' seem to be of only secondary importance in the studied group. When we mentioned the possibility of free dental check-ups through use of mobile dental units, most people who had stopped seeing a dentist were not convinced that they would use them or plainly stated that they would not go, thus providing evidence against the statement 'if you built it, they will come.' (see [13]). This was the more remarkable since the majority of this group admitted that they experienced some degree of oral discomfort. The majority of severely frail people simply did not wish to see a dentist because the perceived benefits were small or non-existent and did not outweigh the perceived required efforts, even if the required efforts would be minimized through provision of dental check-ups at home.

The motives for both continuation and discontinuation of oral care can be understood with help of the Motivational Theory of Life Span Development [50], in particular the Goal Engagement and Goal Disengagement control strategies [51] which form part of this theory. The theory proposes that the key criterion for adaptive development is the extent to which someone realizes control of his or her environment across different domains of life and across the life span. Vital to this theory is the assumption that people try to optimize control over their lives and adjust goals and strategies to achieve this according to their circumstances.

According to the circumstances, someone will either use primary control strategies (directed at changing the environment in order to bring it in line with one's wishes) or secondary control strategies (directed at changing the self to bring it in line with the environment). Secondary control strategies are used when

primary control strategies are not available or fail and comprise (a) adjustment of goals or standards and engaging in self-protective attributions and favorable comparisons (selective secondary control), and (b), in case a goal becomes unattainable, goal disengagement, and freeing up resources (time, effort, motivation, skills) for the pursuit of more attainable goals, sometimes in different domains of life (compensatory secondary control) [50,52].

To most of our participants, the goal of a fresh and clean mouth remained attainable through the practice of tooth cleaning, which rendered a feeling of control that may be seen as a goal in itself ('I can still manage').

With increasing frailty, people compared oral discomfort to other, more troubling, health problems, or attributed it to old age or genetic factors They judged their oral health by comparing it to what they perceived as normal for their age or health situation, and not to a completely healthy mouth (selective secondary control). Many people thought it was normal to have ill-fitting dentures, because they heard so many people complain about them. Hence their norm for 'good oral health' differs from the clinician's norm. This helps explain the discrepancy between normative and perceived treatment need [2,53].

With increasing frailty, people tended to judge that the perceived effort required for seeing a dentist, or, in some cases, brushing their teeth efficiently, did not weigh up against the perceived benefits. They consequently disengaged from the goal (optimal oral health) that motivated these practices. Using compensatory secondary control strategies, they devalued the goal ('oral health is not so important anymore'), lowered the outcome expectation of the behavior ('the dentist cannot help me anyway', or: 'even when I brush, my teeth don't get clean'), adapted to minor oral discomfort, and consciously preserved their motivational resources for more attainable and rewarding goals ('I'd rather use my energy for knitting'), thus providing more insight into the discrepancy between treatment need and service use [1-6].

Contrary to earlier statements implying that frail people discontinue oral care behavior because their impairments render them apathetic [31] (p.200), our findings, in the light of the Motivational Theory of Life Span Development, suggest

that this discontinuation by many frail elderly may be interpreted as an expression of adaptive development. A model guided study is needed to further investigate these assumptions.

In terms of Anderson's and Newman expanded model [54,55], which was originally aimed at predicting health services usage from three dynamics: predisposing, enabling and need factors, our results suggest that predisposing factors, especially health attitudes (the importance attributed to oral health) and beliefs (the difference that a dentist or tooth brushing session can make to general wellbeing, the severity of perceived health risk, and self efficacy) are likely to play a more important role in predicting the oral health behavior of frail elderly, than do need factors, except in case of pain. This finding is supported by earlier evidence regarding dental service use by the elderly [4] and tooth brushing by adults [19] and by many studies on the impact of self efficacy on oral care behavior [18,19,38,45-49].

Methodological strength and limitations

Our study design enabled comparison of perspectives of people with different degrees and characteristics of frailty. Severe cognitive disorders have been shown to have a major impact on oral care behavior as well, but our methodology (interviews) did not allow inclusion of cognitively impaired participants, who generally have worse oral health status and face more barriers to constructive oral health behavior than the majority of our participants [56,57].

As selection of participants was based on voluntarily participation after being informed by the care-manager, it is likely that the number of participants with low socioeconomic status (SES) and with less favorable health behavior and health attitudes was relatively low. These factors are known to reduce willingness to participate in research projects [58]. As a result of this selection bias, themes identified in this study are likely to predominantly represent the views of older people with relatively high SES and relatively favorable oral health attitudes. Based on the expected low number of participants with low SES and on the

exclusion of cognitively impaired people, it can be assumed that oral care behavior among frail Dutch older people is less favorable and perhaps even more affected by physical, cognitive and social impairments than our study suggests.

Although SES, cognitive status and also cultural background are factors that have a proven influence on oral health care in general [56,59-61], we chose to focus on various manifestations and degrees of frailty and to limit the number of varying dimensions to those that we expected to be of major influence, in order to warrant analytical strength. For the same reason, we did not study the effect of character traits.

Interviews were conducted by two researchers who had no background in medicine, geriatrics or dentistry. This probably helped to make participants feel free to inform the interviewers about their 'poor' oral health behavior or unfavorable oral health attitude. However, this also entailed the restriction that self-reported health and oral health issues and experiences with dentists could not always be interpreted against a relevant clinical background during the interview. Regular consultation with the third researcher, a dentist, and with a geriatric dentist helped to overcome this shortcoming. Likewise, we consulted the care-managers to check unclear, implausible, or contradictory information from the participants in order to reduce information bias caused by social desirability.

Implications for dental care professionals and nursing staff

In attempting to improve the oral care behavior of frail elderly, it may be useful to distinguish between factors that prevent people from applying oral care regardless of their wishes (like reduced mobility and dexterity, disorientation, failing memory, and lack of support), and factors that make people unwilling to continue applying oral care any longer (like chronic pain, low energy, low morale).

The first type of factors can be addressed through early signaling of problems and provision of adequate oral hygiene support by nurses. In dealing with the second type of factors, nurses and dental professionals need to first weigh up clinical and oral hygiene related benefits of interventions against the

autonomy of the patient.

Our study contributes to the discussion about the nature and frequency of required professional oral care for this group, and about the allocation of resources, that can be justified either by patient-outcomes or by clinical outcomes. It can be argued that, especially for a population of frail elderly people who are generally more concerned about short term than long term health benefits, clinical outcomes are less meaningful to patients than patient based outcomes, like discomfort and quality of life.

More generally, in evaluations of the efficacy of health services, the perspective of the patient is becoming increasingly important and in some cases even replaces the perspective of the clinicians [62]. Our study results show that, from a patient perspective, resources can be better allocated to support with daily oral hygiene than to dental service use, unless the service is used for relief of perceived pain or discomfort. Perceived health benefits of oral care, besides pain relief, are mainly social and psychological in nature: Functionally impaired elderly people who get help with their oral hygiene perceive that they are still worthy of being cared for. This, in addition to looking and being well-groomed, enhances their sense of self-worth and social worth. This directly improves their quality of life, whereas the perceived health benefits of preventive or even restorative dental visits are not always obvious. Such benefits could not be established in a longitudinal study by Locker [63].

In recent years, provision of dental care through mobile units has become an increasingly widespread practice in Northern European countries, the USA, Canada and Australia [64-69]. It can indeed solve problems for those with oral pain or discomfort who are unable to attend regular dental practices due to lack of transport or mobility problems. However, providing mobile dental care to frail older people regardless of their treatment demands and regardless of their abilities to arrange and make dental visits by themselves, is likely to be cost-ineffective and is also at variance with people's autonomy rights.

The primary aim of dental care should be to keep severely frail people free of oral pain and discomfort. For most residents who were interviewed in this and a

previous study by the same authors [37], this could be achieved by nurses or carers providing necessary support in daily hygiene routines, and through arranging dental visits and transport in cases requiring treatment.

Measures that target the interaction between residents and nursing staff and that increase the quality and level of care without any substantial cost, could relieve most of the barriers to favorable oral care behavior that we observed in this study. Compassionate care and patient centered communication, for instance, are two related approaches that have been proven to enhance the quality of care in care dependent older people [70-74]. They include close observation of patients and effective and empathic communication, and lead to reduction of medical errors and improved health outcomes and patient satisfaction [71]. These approaches are expected to reduce barriers to oral health care encountered in this and other studies [69,75,76], including the invisibility and underreporting of the resident's oral health concerns. Close observation of residents and empathic communication could be used to learn about and understand the resident's concerns and wishes, his or her health priorities, oral health attitude and experienced barriers to good oral hygiene practices.

Dental and nursing staff should also be alert to indicators for poor (oral) hygiene-related behavior, like forgetfulness, depression, or poor dexterity. More specifically, nurses and dentists should regularly ask residents if they experience difficulties in tooth brushing or organizing a dental visit. Compassionate care will help improve the relationship between dentist and patient and between nurse and resident, and may increase the nurse's willingness to support residents with their oral care. As a result, two of the most frequently reported barriers to oral health care support by nursing staff, lack of prioritization and unfavorable oral healthcare attitude [69,75,77-79], may be mitigated.

While several studies have evaluated the effects of training programs for nurses and care-aides aimed at improving oral care support, e.g. [79-82], or have documented barriers to oral care provision for this group, e.g. [83-88], one major barrier to accurate oral care support from nurses remains largely unaddressed. Good oral health of residents is generally not incorporated in the list of

performance indicators that serve to evaluate the quality of a residence and its managers. As long as managers cannot be held responsible for deficient oral health management, implementation of any training program or oral health care guidelines for institutionalized elderly is likely to be ineffective in the long term.

Empowering the patient to express his or her oral hygiene needs may help. Empowering the patient is at least not subject to the usual high staff turnover, time and money constraints and lack of management support that undermine the effectiveness of training programs for health carers [89].

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Chapter 4

Validation of a Dutch version of the Geriatric Oral Health Assessment Index (GOHAI-NL) in care-dependent and care-independent older people

This chapter is an edited version of the published article: Validation of a Dutch version of the Geriatric Oral Health Assessment Index (GOHAI-NL) in care-dependent and care-independent older people. Dominique Niesten, Dick Witter, Ewald Bronkhorst, Nico Creugers. *BMC Geriatrics* 2016;16:53

Abstract

Objective: The aim of this study was to translate the original English version of the GOHAI into a Dutch version (GOHAI-NL), and to test its validity and reliability in care-independent and care-dependent older people.

Methods: The GOHAI questionnaire was translated, discussed by an expert panel, back-translated to the original, pilot-tested and assessed for cognitive and conceptual equivalence. The resulting GOHAI-NL was tested in a group of care-independent (Group A, n = 109, mean age 73.1 ± 5.4 years) and care-dependent (Group B, n = 118, mean age 85.6 ± 7.0 years) cognitively alert people of ≥65 years. Psychometric properties including reliability (internal consistency, item-total, item-dimension, dimension-total, inter-item correlation, and test-retest stability), and validity (convergent, discriminant, known-group), and floor and ceiling effects were assessed.

Results: Internal consistency was confirmed by Cronbach's alphas of 0.86 (group A) and 0.80 (group B). Item-total score correlations were between 0.4 and 0.7 except for item 3 in group A (0.34) and B (0.08) and for item 12 in group A (0.20). Item-dimension and dimension-total correlations were between 0,30 and 0,78 and around 0,7 respectively for the dimensions 'physical functioning' and 'psychosocial functioning', but lower (between 0,13 and 0,44 and around 0,45 respectively) for the dimension 'pain and discomfort'. Average inter-item correlations were 0.34 ± 0.11 (group A) and 0.33 ± 0.08 (group B). Test-retest correlation of the total score (GOHAI-ADD) was 0.88 in group A and 0.93 in group B. Significant correlations in the expected direction were found between GOHAI and most oral health-related variables except for presence of caries in group A, and perceived general health, prosthodontic status and number of natural teeth in group B. No floor effects were detected; however ceiling effects occurred at dimension level.

Conclusion: The GOHAI-NL has satisfactory reliability and validity and can be used to measure OHRQoL in Dutch care-dependent and care-independent older people.

Introduction

A range of instruments that measure oral health-related quality of life (OHRQoL) has been developed in the last two decades. [1]. One of these instruments is the Geriatric Oral Health Assessment Index (GOHAI), a frequently used questionnaire that aims to assess OHRQoL within older populations [2]. It comprises of 12 items that measure three dimensions of OHRQoL: physical function (3 items), psychosocial function (5 items) and pain/discomfort (4 items).

Several studies indicate that the GOHAI is a more suitable instrument to measure OHRQoL of the elderly in Western cultures than the currently most frequently used Oral Health Impact Profile (OHIP) [3–7]. The OHIP taps more severe OHRQoL impacts than the GOHAI and is generally less sensitive to minor impairment of OHRQoL [3]. As a consequence larger proportions of participants report no impact, i.e. have zero-scores (floor effect) when using the OHIP than when using the GOHAI [3, 8]. Based on epidemiological data this floor effect is likely to also occur for Dutch elderly [9, 10]. This effect reduces the ability of the OHIP to detect within-subject changes, when compared with the GOHAI. However, no validated Dutch version of the GOHAI is available.

The aim of this study was to translate the original English version of the GOHAI into a Dutch version (GOHAI-NL), and to validate the translated instrument for use in epidemiological surveys among older people in the Netherlands. To warrant validation for a wide spectrum of older people, we chose to validate the GOHAI for both severely frail, care-dependent older people and for care-independent older people.

Although the GOHAI was originally intended as a self-administered questionnaire, this administration method is likely to generate unreliable results in severely frail and care-dependent older people who often have impairments (e.g. visual, cognitive) that affect their capacity to complete self-administered questionnaires [11, 12]. Therefore, for care-dependent

older people we chose to administer the GOHAI questionnaire through a personal interview.

Methods

Translation

The original GOHAI questionnaire [2] was independently translated into Dutch by two bilingual translators whose native language was Dutch. One of them was a dental researcher experienced in the use of quality of life measures (DN), the other was a professional translator specialized in the translation of patient reported outcome measures. We adhered to the "Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes Measures" [13].

The two forward-translations were reconciled into one forward translation by an expert panel consisting of a dentist-researcher, a geriatric dentist-researcher and an oral health researcher. Competing options were discussed, and other bilingual experts were consulted when necessary, until consensus was reached. The resulting forward-translation was independently back-translated into English by two professional translators whose native language was English. The back-translations were compared for conceptual equivalence with the original GOHAI by the expert panel. Problematic items were identified and discussed among the expert panel and with the translators. Based on their comments, the forward-translation was refined. The resulting translation was tested in a purposive sample consisting of 10 older (65 years and over) people whose self-reported general health was bad ($n = 3$), mediocre ($n = 3$), or good ($n = 4$). The translation was tested for cognitive equivalence and comprehensibility. Based on received comments, the translation was finalized by the expert panel.

Respondent selection

In order to test and validate the proposed GOHAI-NL, participants of 65 years and over were recruited from two independent samples (group A and group B). These two groups were recruited in order to represent distinct differences in frailty and general health within the population of elderly. Group A represented non-frail care-independent older people with expected good health and group B represented frail care-dependent, but cognitively alert people with compromised health. Because gender and dental/prosthodontic status are known to possibly influence self-perceived oral health, for both groups an even distribution of men and women, and of (partially) dentulous (having at least one natural tooth) and edentulous (with or without complete removable dental prostheses (CRDP's)) participants was sought [14–17].

Participants of group A were recruited in the clinic of the Dental School of Radboud University Medical Center through convenience sampling, and comprised of independent living, cognitively alert subjects who came for periodical check-up visits between 2013 and 2015. Since this sample was recruited from a generally healthy, independently living population with no registered health impairments according to the patients' dental records, it was assumed that the chance of recruits being frail would be small. Upon provision of informed consent, after their clinical examination, they were asked to complete a questionnaire, including the GOHAI-NL.

Participants of group B were recruited in a total of 11 residential aged care facilities (RACFs), selected through convenience sampling, in the southern part of the Netherlands. The RACFs were included after the management's consent to have their residents examined on a voluntary base. The care managers of the RACFs recruited the participants for this study, based on instructions by the principal researcher (DN). These instructions included exclusion of subjects who were not cognitively alert

according to the responsible ward nurse. All participants in group B had a certain level of care dependency as determined by a medical authority, based on the Dutch care-dependency classification system (Dutch National Centre for Indication of Care Need (CIZ; www.ciz.nl)). Each RACF resident is assigned a 'Care level Package' (CLP, in Dutch: 'Zorgzwaartepakket') according to this system, indicating the type and intensity of care needed referring to impairments in the physical and/or mental and/or social domain.

Upon provision of their informed consent, the participants received a clinical examination by a final year dental student or a final year dental hygiene student. Next, they were personally interviewed by the principal researcher who used the same questionnaire as the one used for group A.

Convenience quota sampling was used aiming at a total sample size of approximately 120 recruits for each group. Sample size was calculated based on the recommendation to include 5–10 subjects per questionnaire item [18], resulting in a need for 60–120 participants per group.

Data

Participants were asked to provide information regarding their oral health by answering the GOHAI questionnaire and four additional questions: *1. How do you perceive your oral health (very bad, bad, moderate, good, very good); 2. Are you satisfied with your oral health (y/n); 3. Do you think you need dental treatment at the moment (y/n); 4. How do you perceive your general health (very bad, bad, moderate, good, very good).* The GOHAI questionnaire includes 12 questions (each question addressing one oral health item). Respondents were asked how often, in the previous three months, they have experienced the oral health item addressed: 'never', 'seldom,' 'sometimes', 'often', or 'very often or always'. Besides, date of birth, gender, and nationality were recorded. Socioeconomic status (SES) (high, middle, low) was assessed based on last held occupation (according to

the ISCO-08 classification [19]) and on level of education (high, middle, low); the highest level of either education or occupation determined SES.

Clinical data were obtained through examinations by calibrated final year dental students (all kappa's > 0.82; overall κ =0.87; agreement = 90.1 %) or calibrated final year dental hygiene students (all kappa's > 0.66; overall κ =0.74; agreement = 84.4 %). Data included number and position of 1) natural teeth, 2) caries lesions, 3) restorations (such as direct restorations or fixed dental prostheses), and 4) partial or complete removable dental prostheses. The WHO criteria for assessment of the aforementioned variables were used [20]. In addition, clinical treatment need (y/n) was recorded, based on the clinically assessed need for any professional dental treatment including reline, rebase or replacement removable dental prostheses. Group A participants were examined in the clinic of the dental school while group B participants received a clinical examination at their residence, where the examiners used hand held torches and a dental mirror.

Missing data

Participants with two or more GOHAI answers missing, or with one or more answers to the additional questions missing, or with missing clinical data were excluded. In case only one GOHAI answer was missing, the missing value was replaced by mean substitution.

In case clinical data were recorded more than two weeks before or after the questionnaire was completed, the participant was excluded. This was done in order to minimize the chance that the clinical status of the participant was different from that at the moment of completing the questionnaire.

Analyses

General psychometric properties

Answer proportions (%) of each of the GOHAI-NL items and of the GOHAI-ADD (additive) score and the GOHAI-SC (simple count) score [2] were calculated. The GOHAI-ADD score is the sum of all scores (score 1 to 5 per answer; total score from 12 to 60). The GOHAI-SC score is the sum of all items with response 'sometimes', 'often' and 'always or nearly always' (score 0 or 1 per answer; total score from 0 to 12), where a '1'-score indicates impairment for that item [2]. Item scores for questions 3, 5, and 7 were reverse-coded so that all items scored in the same direction; higher values indicating better OHRQoL.

Floor and ceiling effects were assessed at dimension level (with GOHAI dimensions: physical function, pain and discomfort, and psychosocial function), and at total score level (GOHAI-ADD; GOHAI-SC). Floor and ceiling effects were considered present when 20 % or more participants had the lowest (floor) or highest (ceiling) possible total score [21].

Reliability

Reliability was assessed by measuring internal consistency and stability. Internal consistency was measured through correlation between item scores and the overall GOHAI-ADD score, using the corrected item-total score correlation (Spearman's rank correlation coefficient) and Cronbach's alphas. Overall Cronbach's alphas > 0.7 and > 0.9 are considered indicative for acceptable consistency for comparisons at group level and at individual level, respectively [22, 23]. The dimensional structure of the GOHAI-NL was evaluated through assessment of correlations between item scores and the GOHAI-ADD score of the related dimension (subscale). Cronbach's alphas $>$ 0.4 are considered indicative for adequate item-subscale consistency and Cronbach's alphas > 0.7 are considered indicative for adequate subscale-overall scale (total score) consistency [22]. Inter-item correlations were

calculated in order to determine the extent to which the items were related to each other (average inter-item correlation ideally should be between 0.2 and 0.5 [23, 24]), and to detect redundancy of items (Cronbach's alpha > 0.7) [25].

Stability was assessed by measuring test-retest reliability through calculation of intraclass correlation coefficients (ICCs) (two-way mixed, single measure) in two subsamples consisting of randomly selected respondents from group A and group B. Participants of these samples groups were either sent a second questionnaire (group A) or interviewed a second time (group B) after one to two weeks after they had returned their first questionnaire or were interviewed, as it was expected that no major differences in oral status and oral health would have occurred during this time interval. ICC values > 0.75 were considered indicative for excellent stability, 0.40 – 0.75 for fair to good, and < 0.40 for poor stability [26].

Validity

Validity was measured through convergent validity, discriminant validity, and known-group validity.

Convergent validity refers to the degree to which two measures that should measure the same construct, are related. This was determined through assessment of the correlations between GOHAI-ADD scores and the answers to two general questions on self-perceived oral health: 1. How do you perceive your oral health; 2. Are you satisfied with your oral health.

Discriminant validity refers to the degree to which two measures that should measure two similar, but conceptually different constructs are related. This was determined through the correlation between the GOHAI-ADD scores and 1. clinical treatment need; 2. presence of caries lesions; and 3. self-perceived general health. A low to moderate correlation was expected between higher GOHAI-ADD scores on the one hand and less

clinical treatment need, absence of caries lesions, and better self-perceived general health on the other.

Known-group validity refers to the degree to which a measure is sensitive to differences within subgroups that are assumed to be reflected in the scores. This was assessed by comparing differences in GOHAI-ADD scores between subgroups with different self-perceived treatment need (y/n), a higher number of natural teeth, and different dental / prosthodontic status (natural teeth without removable dental prostheses (RDPs), natural teeth with partial or complete RDPs, or no natural teeth (with or without complete RDPs)). Participants without self-perceived treatment need, with higher numbers of natural teeth, and without removable dental prostheses, were assumed to have higher GOHAI-ADD scores.

Correlations were assessed by calculating Spearman's rank correlation coefficients (r), with values > 0.5 indicating a strong correlation, 0.35 to 0.5 a moderate correlation, and 0.2 to 0.34 a low correlation [27, 28].

Ethics, consent and permissions

The study was approved by the Medical Ethics Committee (CMO) of the Radboud University Nijmegen Medical Center (CMO ref. 2012/294). All participants were informed (in writing and personally) about the study and provided written consent prior to their participation.

Results

Translation

Translation procedures and discussions among the expert panel yielded no irresolvable issues concerning semantic, experiential or conceptual equivalence. The resulting GOHAI-NL is presented in Appendix 1.

Characterization of groups and subjects

The original sample consisted of 232 participants; 111 in group A and 121 in group B. After exclusion of subjects because of 2 or more missing GOHAI answers (group A; $n = 2$) or missing clinical data (Group B; $n = 3$) respectively, group A included 109 participants and group B 118 (Table 1). For two participants in group A who missed one GOHAI question, the mean substitution was imputed. In group A, 47.7 % of the participants were female; 60.6 % were dentate (at least one natural tooth) and the mean age was 73.1 ± 5.4. In group B, 57.6 % were female; 49.2 % were dentate and the mean age was 85.6 ± 7.0. Group A participants had a slightly higher SES (high 31.9 %, medium 50.5 %, low 17.8 % versus high 23.9 %, medium 40.2 %, low 35.9 % in group B).

General psychometric properties

Answer proportions and percentage impairment (based on the number of answers 'sometimes', 'often' or 'nearly always or always') for group A and B are listed in Table 2. The mean GOHAI-ADD score was 51.6 ± 7.4 (range 29–60) for group A and 52.3 ± 6.1 (range 26–60) for group B. Mean GOHAI-SC score was 1.9 ± 2.4 (range 0–9) for group A and 1.9 ± 1.9 (range 0–9) for group B. The items that showed highest frequency of impairment were item 9 (30.2 %), item 2 (28.5 %), and item 5 (23.8 %) for group A and item 2 (48.3 %), item 7 (39.8 %), and item 5 (26.3 %) for group B, indicating that most impairment was reported in relation to oral function (items 1, 2 and 4) and psychological aspects (items 6, 7, 9, 10, 11) (Table 2). The items that showed lowest frequency of impairment were items 6, 8, and 10 for both groups, indicating that least impairment was reported in relation to psychosocial aspects, which was emphasized by the zero scores in answer categories 'often' and 'nearly always or always' of items 6, 9, 10, and 11.

Table 1. Sample Characteristics and Analyses per Sample

Sample	Number	Age *Mean* (SD)	Gender *%female*	Dentate[a] %	Data administration	Analyses
Group A: Independent living dental clinic attenders of 65+ yrs (check-up visits)	109	73.1 (5.4)	47.7	60.6	questionnaire	general psychometric properties, floor and ceiling effects, internal consistency (item-total scale, dimension-total scale, inter-item), convergent, discriminant, and known-group validity
Group B: Institutionalized care-dependent elderly of 65+ yrs	118	85.6 (7.0)	57.6	49.2	personal interview	general psychometric properties, floor and ceiling effects, internal consistency (item-scale, dimension-scale, inter-item), convergent, discriminant, and known-group validity
subsample (convenience sample) of group A	32	74.0 (5.8)	50.0	78.1	questionnaire	test-retest reliability
subsample (convenience sample) of group B	34	85.9 (6.9)	47.1	50.0	personal interview	test-retest reliability

[a]minimum of 1 natural tooth

No floor or ceiling effects were detected at total score level (GOHAI-ADD): 7.3 % (group A) and 12.7 % (group B) had the highest possible score of 60, none had the lowest possible score of 12. The GOHAI-SC score however did show a floor effect: 42.2 % of group A participants and 28.0 % of group B participants had a total score of zero. At dimension level, there were no floor effects. However, ceiling effects occurred in two dimensions in group A and in all 3 dimensions in group B. Maximum scores were obtained by 37.6 % (physical function), 21.1 % (pain and discomfort) and 17.4 % (psychosocial function) of group A participants; and by 28.0 % (physical function), 28.8 % (pain and discomfort), and 28.0 % (psychosocial function) of group B participants.

Table 2. Answer proportions and percentage participants scoring 'impairment'[a] per GOHAI item for groups A and B[b]

GOHAI item	group	never	seldom	sometimes	often	very often or always	% impairment
1. Limit the kinds of food	A	64.2	14.7	10.1	6.4	4.6	21.1
	B	61.9	16.1	11.9	5.9	4.2	22.0
2. Trouble biting or chewing	A	39.4	32.1	13.8	8.3	6.4	28.5
	B	34.7	16.9	14.4	22.9	11.0	48.3
3. Able to swallow comfortably	A	7.3	5.5	5.5	19.3	62.4	18.3
	B	7.6	2.5	5.9	15.3	68.6	16.0
4. Unable to speak clearly	A	70.6	18.3	7.3	0.9	2.8	11.0
	B	77.1	5.9	11.9	2.5	2.5	16.9
5. Able to eat without discomfort	A	6.4	10.1	7.3	24.8	51.4	23.8
	B	2.5	8.5	15.3	28.0	45.8	26.3
6. Limit contact with people	A	86.2	10.1	1.8	0.9	0.9	3.6
	B	93.2	5.9	0.8	0.0	0.0	0.8
7. Pleased with look of teeth	A	3.7	4.6	8.3	56.9	26.6	16.6
	B	11.0	14.4	14.4	29.7	30.5	39.8
8. Used medication to relieve pain	A	70.6	21.1	7.3	0.9	0.0	8.2
	B	93.2	3.4	1.7	0.8	0.8	3.3
9. Worried about teeth, gums or dentures	A	37.6	32.1	16.5	12.8	0.9	30.2
	B	65.3	16.9	15.3	2.5	0.0	17.8
10. Self-conscious of teeth, gums or dentures	A	67.9	21.1	9.2	0.0	1.8	11.0
	B	84.7	9.3	5.9	0.0	0.0	5.9
11. Uncomfortable eating in front of others	A	70.6	14.7	9.2	3.7	1.8	14.7
	B	82.2	11.0	5.9	0.8	0.0	6.7
12. Sensitive to hot, cold or sweet foods	A	47.7	32.1	15.6	3.7	0.9	20.2
	B	68.6	9.3	13.6	7.6	0.8	22.0

[a]combined answers 'sometimes','often', and 'very often or always'; reverse coded for items 3, 5, 7
[b]Group A: care-independent subjects, $n = 109$; Group B: care-dependent subjects, $n = 118$

Reliability

Cronbach's alphas were 0.86 for group A and 0.80 for sample B, indicating good overall internal consistency. The corrected item-total score correlations were between 0.4 and 0.7 indicating adequate correlation, except for item 3 in both group A ($r = 0.34$) and group B ($r = 0.08$), and for item 12 in group A ($r = 0.20$) (Table 3).

Inter-item correlations were within the acceptable range of 0.2–0.5 for both groups (mean Cronbach's α group A: 0.34 ± 0.11; mean Cronbach's α group B: 0.33 ± 0.08). Inter-item correlations > 0.7 occurred only in group

A, between items 1 and 2 (Cronbach's $\alpha = 0.76$) and between items 10 and 11 (Cronbach's $\alpha = 0.74$); indicating possible redundancy.

Test-retest reliability (stability) was high for both groups: mean 0.88 (GOHAI-ADD) and 0.87 (GOHAI-SC) for group A, and 0.93 (GOHAI-ADD) and 0.89 (GOHAI-SC) for group B. ICCs of 0.62 - 0.88 in group A and 0.64 – 0.91 in group B indicated overall good stability, with least stability for items 3, 6 and 7 in group A, and for items 7, 9, and 11 in group B (Table 3).

Table 3. Reliability analysis based on item-total score correlation and test-retest correlation

GOHAI item	Corrected Item-Total score cor-relation Group A	Cronbach's Alpha if Item Deleted	Test-retest corre-lation ICC[a]	Corrected Item-Total score correlation Group B	Cronbach's Alpha if Item Deleted	Test-retest correla-tion ICC[a]
1. Limit the kinds of food	0.65	0.84	0.75	0.61	0.77	0.91
2. Trouble biting or chewing	0.67	0.84	0.81	0.53	0.78	0.91
3. Able to swallow comfortably	0.34	0.86	0.62	0.08	0.83	0.74
4. Unable to speak clearly	0.63	0.84	0.86	0.40	0.79	0.94
5. Able to eat without discomfort	0.49	0.85	0.78	0.67	0.77	0.74
6. Limit contact with people	0.43	0.85	0.64	0.47	0.80	0.79
7. Pleased with look of teeth	0.62	0.84	0.68	0.58	0.78	0.69
8. Used medication to relieve pain	0.51	0.85	0.74	0.53	0.79	0.81
9. Worried about teeth, gums or dentures	0.60	0.84	0.80	0.51	0.78	0.64
10. Self-conscious of teeth, gums or dentures	0.69	0.84	0.79	0.52	0.79	0.73
11. Uncomfortable eating in front of others	0.74	0.83	0.88	0.61	0.78	0.64
12. Sensitive to hot, cold or sweet fools	0.20	0.87	0.73	0.43	0.79	0.82

[a]ICC Intraclass correlation coefficient; applied to subsamples of group A ($n = 32$) and B ($n = 34$)

The dimensional structure of the original GOHAI was only partly supported by Cronbach's alphas and item-subscale correlation values (Table 4). Cronbach's alphas for subscale-overall scale correlation were around the threshold of 0.7 for the dimensions 'physical functioning' and 'psychosocial functioning', and all item-subscale correlations within these dimensions were adequate (above > 0.45) except for item 4, 'trouble speaking clearly', in group B. Items within the dimension 'pain and discomfort' (items 3, 5, 8, 12) were only weakly correlated to the dimension

total score (Cronbach's alphas between 0.13 and 0.44). This dimension showed inadequate (<0.7) subscale - overall scale consistency in both groups A and B.

Table 4. Correlation between item - subscale (dimension) scores and between subscale-overall scale scores

GOHAI items and dimension	Group	Cronbach's alpha
Dimension: Physical Functioning; subscale-overall scale Cronbach's α: group A: 0.82; group B: 0.64		
1. Limit the kinds of food	A	0.78
	B	0.54
2. Trouble biting or chewing	A	0.81
	B	0.55
4. Unable to speak clearly	A	0.49
	B	0.30
Dimension: Pain and discomfort; subscale-overall scale Cronbach's α: group A: 0.43; group B: 0.49		
3. Able to swallow comfortably	A	0.31
	B	0.19
5. Able to eat without discomfort	A	0.31
	B	0.36
8. Used medication to relieve pain	A	0.26
	B	0.44
12. Sensitive to hot, cold or sweet foods	A	0.13
	B	0.28
Dimension: Psychosocial functioning; subscale-overall scale Cronbach's α:group A: 0.82; group B: 0.72		
1.Limit contact with people	A	0.46
	B	0.46
2. Pleased with look of teeth	A	0.65
	B	0.59
9. Worried about teeth, gums or dentures	A	0.52
	B	0.65
10. Self-conscious of teeth, gums or dentures	A	0.76
	B	0.59
11. Uncomfortable eating in front of others	A	0.76
	B	0.48

Validity

Table 5 shows the main results of comparisons between assumedly construct-related variables and GOHAI-ADD scores.

Table 5. Validity assessments: Spearman's rank correlations between selected variables and GOHAI-ADD scores

Type of validity		*Group A*			*Group B*		
variable	answer categories	n	Mean GOHAI-ADD score (SD)	correlation (r), p-value	n	Mean GOHAI-ADD score (SD)	correlation (r), p-value
Convergent validity							
perceived oral health							
	very bad	0	-	r=0.42	2	31.5 (7.8)	r=0.68
	bad	1	31.0 (-)	p < 0.001	13	44.5 (6.7)	p < 0.001
	moderate	23	46.2 (8.3)		23	49.3 (5.7)	
	good	83	53.1 (6.1)		53	53.6 (4.2)	
	very good	2	59.0 (0.0)		26	57.8 (2.6)	
satisfied with oral health							
	yes	93	53.3 (6.0)	r=0.47	84	54.7 (4.5)	r=0.52
	no	15	41.7 (7.8)	p < 0.001	34	46.3 (7.2)	p < 0.001
Discriminant validity							
perceived general health							
	very bad	NA	NA	r=0.24	3	52.0 (8.5)	r=0.10
	bad	1	59.0 (-)	p=0.014	24	51.2 (7.7)	p=0.30
	moderate	21	47.6 (4.5)		38	52.1 (6.3)	
	good	74	52.0 (6.8)		49	52.9 (6.5)	
	very good	11	55.6 (5.0)		4	54.3 (4.3)	
clinical treatment need							
	yes	40	48.6 (8.6)	r=0.29	65	50.5 (6.4)	r=0.36
	no	69	53.3 (6.2)	p=0.002	53	54.5 (6.3)	p=<0.001
at least one tooth with caries**							
	yes	7	52.5 (5.1)	r=0.08	32	50.7 (5.9)	r=0.42
	no	59	53.2 (6.0)	p=0.55	26	55.2 (5.5)	p=0.001
Known-group validity							
dental/ prosthodontic status							
	natural teeth without RDP	44	54.4 (4.6)	r=0.29	24	53.7 (6.3)	r=0.07
	natural teeth with RDP	22	50.7 (7.4)	p=0.003	34	51.9 (6.0)	p=0.44
	no natural teeth	43	49.1 (8.8)		60	52.0 (7.1)	
no. of natural teeth** (1-32)		66		r=0.39	58		r=0.24
				p<0.001			p=0.067
perceived need for treatment							
	Yes	45	48.1 (8.2)	r=0.48	33	46.3 (7.5)	r=0.53
	No	63	54.8 (5.3)	p < 0.001	85	54.6 (4.5)	p < 0.001

Other correlations							
gender							
	female	52	50.3 (8.0)	r=0.17	68	52.4 (6.8)	r=0.01
	male	57	52.7 (6.8)	p=0.08	50	52.2 (6.5)	p=0.88
age	(65-100)			r=0.09			r=0.09
				p=0.34			p=0.36
SES	high	34	53.0 (6.0)	r=-0.18	28	54.2 (5.4)	r=-0.14
	middle	54	51.4 (7.7)	p=0.07	47	52.1 (7.3)	p=0.13
	low	19	48.8 (8.7)		42	51.3 (6.5)	

*r = Spearman's rank correlation coefficient
**subjects with at least 1 natural tooth

Convergent validity: moderate to high (0.42–0.68), significant correlations in the expected direction were found between GOHAI-ADD scores for self-perceived oral health and satisfaction with oral health for both groups A and B.

Discriminant validity: low to moderate (0.24–0.42), but significant correlations in the expected direction were found between GOHAI-ADD scores and self-perceived general health (group A), clinical treatment need (group A and B) and presence of caries (group B). Non-significant were the correlations between self-perceived general health (group B), and presence of caries (group A); these correlations found were, however, in the expected direction.

Known-group validity: moderate, significant correlations in the expected direction (group A: r = 0.48; group B: r = 0.53) were found between GOHAI-ADD scores and self-perceived treatment need. GOHAI-ADD scores were also significantly correlated in the expected direction for dental / prosthodontic status (r = 0.29) and number of natural teeth (r = 0.39) for group A, but not for group B.

Differences in age, gender and SES were not statistically significantly correlated with GOHAI-ADD; however higher SES levels were correlated with higher GOHAI-ADD scores in both groups (Table 5).

Discussion

Study design

This study tested psychometric properties of a Dutch version of the GOHAI, including validity and reliability. The original GOHAI was validated in a population of older well-educated Americans. Although the GOHAI has been demonstrated to also be valid for younger and for less educated population samples [29, 30], it remains important that validity problems related to differences in language or culture are ruled out. This is why we undertook an evidenced approach [13] to assure conceptual equivalence between the GOHAI-NL and the original GOHAI.

Following the vast majority of GOHAI validation studies, we calculated GOHAI-SC scores in addition to the standardly used GOHAI-ADD scores. Although the use of GOHAI-SC scores implies some loss of information because it requires dichotomization of GOHAI answers, the GOHAI-SC provides a reliable, albeit crude, estimate of perceived oral impairments.

To our knowledge, our study is the first that validates the GOHAI in two distinct groups of older people using different administration methods. This choice was prompted by the evidence that the use of self-administered questionnaires in severely frail older populations does not always yield reliable results [31]. We therefore used personal interviews as the administration method in this group. When using personal interviews, any problems related to cognitive abilities of the respondent can be detected more easily. Although the GOHAI has been used in people with mild cognitive impairments [32, 33] it has not been validated for such populations. Therefore we do not recommend the use of the GOHAI-NL in cognitively impaired subjects except when closely related informants provide support in answering questions, and with explicit reference to this fact.

Limitations

The administration method used in group B may have induced a degree of social desirability bias, leading to expectedly 'too high' scores. Reissmann *et.al.* [34] showed that OHIP outcomes obtained through personal interviews were significantly lower (indicating less oral health-related complaints) than outcomes derived from self-administered questionnaires in a group of older adults. In the present study, we could not examine the effect of these two administration methods on GOHAI-scores because these methods were applied in different samples. It is recommended to compare the effects of different methods of administration on acquired GOHAI scores within groups of frail and non-frail older people in future research.

Our study did not measure responsiveness to change in oral health status of the GOHAI-NL and hence additional longitudinal research is recommended to assess the sensitivity of the GOHAI-NL for monitoring oral health changes.

Results

In the translation procedure, the expert panel decided to use the Dutch equivalent of 'very often or always' instead of 'always' in the original version. This follows the reasoning used in the translation to the German GOHAI [5]: 'always' ('altijd') in Dutch is very strictly interpreted as 'not a moment without', and the distance between the alternative response options 'often' and 'very often or always' is expectedly more equal to the distances between other consecutive response options, as meant in a Likert-scale [35], than the (expectedly larger) distance between 'often' and 'always'.

The double negative phrasing of item 5 of the original GOHAI "how often were you able to eat *without discomfort*" has been documented to lead to inconsistent answers [30, 36]. In our study, item 5 had relatively low item-total correlation in group A and around 6 % of the answers to (the

self- administered) item 5 were considered to be inconsistent with reference questions. The effect of double negative phrasing may be mitigated through adding reading notes to the questionnaire; which should be considered for all international GOHAI versions.

The mean GOHAI-ADD scores of 51.6 ± 7.4 in group A and of 52.3 ± 6.1 in group B in this study are similar to those found in Northwestern Europe and the USA (53 in Germany, 49.8 in Sweden, 46.4 in France, and 52.5 in the USA) [2, 30, 37, 38] but higher than those found elsewhere in the world (mean GOHAI-ADD scores between 18 and 49 in Romania Hongkong, Japan, Malaysia, Jordan, Turkey, India, Spain, Mexico, Iran, see also overview in Rezaei *et.al*. [39]). This is considered to be not only due to differences in oral health status, but also to variations in perceptions and expectations of oral health as well as in the self-reporting of oral health impacts, which are in part explained by cultural differences.

Although GOHAI outcomes of groups A and B are not meant to be compared without reference to the fact that different administration methods were used, the lack of difference between GOHAI-ADD scores is striking against the differences in clinically assessed oral health status between both groups (group B having worse oral health). The relatively high GOHAI scores of group B could be partially explained by social desirability bias (as addressed above) and by the so-called 'disability paradox' of older people that implies that they have better self-perceived oral health despite worse oral health status [40, 41].

Contrary to the OHIP [3, 6, 8], the GOHAI did not demonstrate floor and ceiling effects for the overall GOHAI-ADD score, which is the most used outcome measure for group comparisons of the GOHAI. At subscale (dimension) level, however, floor effects were detected. This means that the subscales are not capturing the full range of potential GOHAI responses in the population and that the ability to detect changes over time may be compromised [42].

Regarding reliability: both overall internal consistency (Cronbach's alphas of 0.86 (group A) and 0.80 (group B)) and overall stability (Cronbach's alphas of 0.88 (group A) and 0.93 (group B)) were good and comparable with values of other GOHAI studies [5, 8, 30, 37, 39, 43–46]. Items 3 (ability to swallow) and 12 (sensitivity to hot, cold and sweets) showed low correlation with the total GOHAI scores, which is in line with several previous validation studies [5, 30, 39, 47, 48]. Both items probably refer to a different construct than that intended to be measured by the GOHAI, i.e. oral health-related quality of life. One respondent in our study criticized item 12 saying that any human tissue is sensitive to hot and cold. Hence apart from the questionable conceptual correlation between teeth and tissue sensitivity and oral health, ambiguous interpretation of this item is likely to contribute to the found low item-total correlation.

The subscale (dimension)-overall scale correlation for the dimension 'pain/discomfort' was too low to justify distinction of this dimension. Since this finding is supported by ample evidence against the original dimensional structure of the GOHAI [5, 36, 37, 45, 49], it may be worthwhile to reconsider these dimensions or opt for a one-dimensional scale.

Regarding validity: the GOHAI-NL was in good agreement with other measures of perceived oral health and demonstrated overall good convergent and adequate discriminant and known-group validity, supporting its construct validity. The low correlation between presence of carious lesions and GOHAI-ADD scores in the care-independent elderly could be partly due to the low numbers of carious lesions encountered in group A, where only 7 out of 66 dentates had one or more carious teeth. The low correlations between GOHAI-ADD scores on the one hand and self-perceived general health and dental/ prosthodontic status on the other that were found in this study in the group of care-dependent elderly, were unexpected. Although there is some evidence indicating that the correlation between general health and oral health is weaker in populations with impaired

general health in comparison to healthy populations, generally the association between perceived oral health and perceived general health is strong [50, 51].

With regard to prosthodontic status, the lack of correlation, which is in contrast with findings from the majority, but not all GOHAI validation studies (e.g. [5, 30, 37, 44] vs. [39, 49]), may be due to the adaptation of frail elderly to oral discomfort caused by removable dental prostheses [52, 53].

Conclusion

This study shows that the GOHAI-NL has satisfactory reliability and construct validity and can be used to measure OHRQoL in Dutch care-dependent and care-independent older people.

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Chapter 5

Oral health-related quality of life and associated factors in a care-dependent and a care-independent older population

This chapter is an edited version of the published article: Oral health-related quality of life and associated factors in a care-dependent and care-independent population. Dominique Niesten, Dick Witter, Ewald Bronkhorst, Nico Creugers. *J Dentistry* 2016;55:33-9

Abstract

Objective: The study aim was to examine relationships between oral health (OH) factors and general health (GH) factors (including physical, mental, and social health domains) and OHRQoL in a care-independent and a care-dependent older population.

Methods: Care-independent participants (n = 109) were recruited from the Nijmegen dental school; care-dependent participants (n = 126) from residential aged care facilities. Data collected included: OHRQoL (Geriatric Oral Health Assessment Index (GOHAI)), age, gender, socioeconomic status, number of teeth and occluding pairs, presence of carious teeth, presence of removable dental prostheses, clinically assessed treatment need (CTN), self-reported GH, and, for care-dependent participants: care-dependency level and health domain variables: physical, mental (SF-12: Physical and Mental Component Summary scores), and social (ENRICHD social support index). Multiple linear regression analyses were performed to assess associations with GOHAI scores.

Results: Mean GOHAI scores of care-independent and care-dependent participants did not differ significantly despite considerably worse OH status of the latter. Regression models revealed significant ($p \leq 0.05$) associations between GOHAI scores and age and CTN (and near-significant with prosthodontic status ($p=0.053$)) in care-independent participants ($R^2 = 0.19$) and only with CTN in care-dependent participants ($R^2 = 0.09$). Self-reported GH was not significantly associated with GOHAI; when substituted by the health domain variables, only social support was significantly associated with GOHAI scores.

Conclusions: GOHAI outcomes are associated with different variables in care-independent and care-dependent older subjects. In care-dependent subjects, GOHAI outcomes are more strongly related to social support than to OH factors or other GH factors. GOHAI outcomes should not be compared across care-dependent and care-independent populations without careful interpretation of these outcomes against specific factors that distinguish such populations, like health factors and living environment.

Introduction

Over the last two decades, outcomes from oral health-related quality of life (OHRQoL) questionnaires have become widespread and common indicators of self-reported oral health [1]. The use of OHRQoL measures and the interpretation of its outcomes, however, is not without controversy [1-4]. Several studies have shown that associations between clinical indicators of oral health and OHRQoL outcomes are weak in older populations [5, 6]. Time and again, older people have reported better OHRQoL than young or middle-aged adults despite their generally worse oral health conditions [7-10].

Perhaps the most plausible explanation for the found discrepancies between oral health status and OHRQoL outcomes is that the pathways connecting these issues are mediated by personal and environmental variables [11]. Apart from personal characteristics, changes in values and meanings influence people's perceptions of and reactions to (oral) diseases or disorders, and shape processes of coping and adaption [12-14]. Such changes include adaptation to oral impairments [6] which often come with ageing, but also with health decline and other life changing events.

It can therefore be assumed that in care-dependent (i.e. "having limited, health-associated abilities to meet self-care demands" [15]) older people, oral health impairments have less impact on QoL than in care-independent older adults. Changes in values and meanings amongst care-dependent institutionalized populations may also be induced by reduced social health. Social health can be measured by a broad range of aspects, of which the most important are related to the extent and quality of perceived social support [16-18]. Lack of social support is associated with being institutionalized [19, 20] and has a proven negative effect on life satisfaction and QoL in general [21, 22].

Although the effect of age on the relationship between oral health status and OHRQoL has been demonstrated previously [5, 7-9, 23], it is unclear if and how this relationship differs between groups with different general health status To our knowledge, only few studies have addressed this issue [5, 24-27]. Three

of these studies reported a significant association between better (self-reported) general health and better OHRQoL, regardless of age and oral health status. Only one study has addressed the association between care-dependency and OHRQoL. Zenthöfer *et.al*. (2014) found that care-dependency level was inversely related to OHRQoL, although the number of respondents in this study was too low to derive any solid conclusions [24]. We found no studies that documented the associations between variables representing three separate health domains (physical, mental, and social) and OHRQoL.

In light of the findings presented above, we posed the questions 1) if OHRQoL in institutionalized, care-dependent older people has a different pattern of associations in terms of oral health and general health when compared to home dwelling care-independent older people, and 2) if, in care-dependent older people, the size of the associations between OHRQoL and separate health domains (physical, mental, and social health) differ.

Gaining more insight into association patterns of OHRQoL outcomes and oral health factors and general health factors in people with and without health impairments enables us to better understand how oral health and OHRQoL are related. It also tells us if OHRQoL outcomes can be meaningfully compared between groups of different general health or care-dependency status.

Thus the aim of this study was to examine to what extent oral health factors and general health factors are associated with OHRQoL in care-dependent and care-independent older people.

Methods

Population and samples

Participants aged 65 years and over who were cognitively alert were recruited in two populations: a population of care-independent, home dwelling people (Group A) and a population of care-dependent institutionalized people with varying levels of care-dependency (Group B). Group A participants were recruited through convenience sampling of patients of the university dental

clinic who visited the clinic for a regular dental check-up visit. Group B participants were recruited through contact managers of randomly chosen residential aged care facilities (RACFs) in South-East Netherlands.

Purposive sampling was applied in both groups, aimed at achieving adequate numbers of subjects with regard to variables whose outcomes were known prior to sampling and that have been found to influence OHRQoL (i.e. gender, prosthodontic status (dentate/ edentate) and levels of care-dependency) [5, 25, 28]. The study was approved by the Medical Ethics Committee (CMO) of the Radboud University Nijmegen Medical Center (CMO ref. 2012/194). All recruits gave informed consent in writing to participate in the study.

Clinical data and care-dependency

Clinical data were obtained through clinical oral examination according to WHO criteria [29] by final year calibrated dental students (all κ's > 0.82; overall $\kappa = 0.87$; agreement = 90.1%) and calibrated final year dental hygiene students (all κ's > 0.66; overall $\kappa = 0.74$; agreement = 84.4%). Data included number and position of teeth, presence of carious teeth, and presence of removable dental prostheses (RDPs). Clinical assessment of treatment need (y/n) was also recorded and comprised any need for professional dental treatment including reline, rebase or replacement of RDPs, and periodontal treatment . With regard to prosthodontic status, three categories were distinguished: people with at least one natural tooth and without RDPs, people with at least one natural tooth and one or more RDPs, and people without natural teeth with complete RDPs.

With regard to health status and care-dependency, we distinguished between care-independent participants (Group A) with no major (general) health impairments according to the medical details in patients' dental records and with no clinically indicated (general) health care need, and care-dependent participants (group B). Group B participants had care-level-package 1 (CLP1;low dependency) through 6 (CLP6; high dependency) according to the

Dutch national care-level package classification system. In this system, the intensity and type of care needed is regularly determined by a medical authority and based on the intensity and type of clinically indicated functional impairments (in the physical and/or psychological and/or social domain) [30]. People with care-level package 5 were excluded since this level comprises predominantly cognitive impairment.

Self-reported data

Data on OHRQoL, self-reported general health*'(very bad/ bad/ moderate/ good/ very good)*, and treatment demand (*y/n*) were obtained by a questionnaire, as described in Chapter 4. OHRQoL was measured using the validated Dutch version of the Geriatric Oral Health Assessment Index (GOHAI) [31]. The GOHAI consists of 12 questions on experienced functional and psychosocial impacts of oral health, scored on a 1-5 point Likert scale with higher scores indicating better OHRQoL. Additional data were collected on age, gender, and socioeconomic status (SES). SES (high, middle, and low) was determined on the basis of the highest level of either education (high, middle, and low) or last held occupation (according to the ISCO-08 classification [32]).

Since we assumed, based on patient records and the absence of a medically assessed care-need indication, that group A participants generally would have good health, we assessed impairments in the physical, mental and social health domains only for group B. Physical and mental health were assessed through the SF-12 Short Form health survey [33]. Answers to SF-12 questions were used to compute a physical component summary (PCS) score and a mental component summary (MCS) score. The scores are calculated using indicator variable weights, with the mean scores set at 44.06 (PCS) and 49.50 (MCS), which are the age and sex-standardized norm scores for the 70-79 age group in the Dutch population [34]. Higher scores indicate better health. Social support was used as a proxy measure for social

health, and was assessed through the validated ENRICHD Social Support Index (ESSI) [35, 36]. The ESSI consists of seven items/ questions that assess the four defining attributes of social support: emotional, instrumental, informational, and appraisal [37]. Six out of seven ESSI items are scored on a 1-5 point Likert scale, higher scores reflecting more social support. The last item covers marital status, where 1 point (without partner) or 5 points (with partner) can be obtained. Total scores of 7 – 18 represent a low level of social support; 19 - 26 medium and 27 – 35 a high level of social support [37].

Statistical analysis

SPSS version 22.0 (SPSS Inc., Chicago, IL, USA) was used for data analyses. Given the robustness of parametric tests to deviations from data normality, and given the higher power of these tests [38], we chose to use parametric tests for analyses of GOHAI outcomes. One-way ANOVA, followed by Welch F tests in case of non-homogeneous variances, followed by posthoc tests (Tukey or Tamhane's T2 in case of non-homogeneous variance) were used to assess significant differences ($p<0.05$) in mean GOHAI scores between categories. Continuous variables (age, number of teeth and number of occluding pairs) were correlated with GOHAI scores using Pearson's correlation coefficients.

Multiple linear regression analyses were performed to examine, for both groups A and B, the associations between OHRQoL (dependent variable) and three sets of explanatory variables which were added in three stages using the 'enter' method. In order to check potential violation of assumptions for linear regression tests, homoscedasticity (equal variances) and normality of standardized residuals were checked through Q-Q-plots [39]. Multicollinearity (inter-dependency of variables) was tested through calculation of variance inflation factors (VIFs): variables with VIFs ≥ 2.5 were not included in the models. The first model included background variables

with a known potential confounding effect (age, gender, and SES). In a second model, clinically assessed variables that represented oral health (including prosthodontic status) were added. In a third model, variables that represented general health (including care-dependency) were added.

In order to compare differences in pattern of associations (between GOHAI outcomes and OH and GH variables) between group A and B, predicted GOHAI outcomes according to the third models for group A and B were calculated for all respondents (i.e. n=235) based on the models' respective constants and partial regression coefficients. Differences in association patterns were analyzed using a Pearson correlation test and through calculation of the mean of the absolute differences between predicted GOHAI outcomes based on Model A and Model B. Differences were visualized through a scatterplot of paired predicted outcomes, where points should lie close to the line x=y in case of small differences.

Additional regression analysis was carried out in Group B in order to examine the associations between three specific health domains (physical, mental, and social) and OHRQoL.

Minimal sample size was determined to allow for multiple linear regression with a maximum of 9 (Group A) and 12 (Group B) independent variables, based on the presumption that a minimum of 10 participants for each independent variable is required for meaningful outcomes [40].

Results

Sample characteristics are displayed in Table 1. GOHAI scores in Groups A and B were similar: mean Group A: 51.6 ± 7.4 (range 29-60), mean Group B: 52.1 ± 6.7 (range 26-60); Clinical oral health outcomes of care-dependent participants were significantly worse than those of care-independent participants (16.8 ± 8.2 *vs*. 10.7 ± 5.1 missing teeth, 5.4 ± 5.0 *vs.* 9.4 ± 3.5 occluding pairs of natural teeth; 59% *vs.* 37% subjects with clinically assessed treatment need, 57% *vs.*11% subjects with one or more carious teeth).

Table 1. Group characteristics and mean GOHAI scores of care-independent home dwelling older people (group A) and care-dependent older people in residential aged care facilities (group B).

Group characteristics	Group A (n = 109)		Group B (n = 126)	
		GOHAI mean (SD)		GOHAI mean (SD)
GOHAI score		51.6 (7.4)		52.1 (6.7)
Age (years); mean (SD)	73.1 (5.4)		85.4 (7.1)	
Gender; (n (%))				
- female	52 (48)	50.3 (8.0)	73 (58)	52.2 (6.9)
- male	57 (52)	52.7 (6.8)	53 (42)	51.9 (6.6)
SES (Group A: n=107); (n (%))				
- low	19 (18)	48.8 (8.7)	48 (38)	51.3 (6.4)
- medium	54 (50)	51.4 (7.7)	50 (40)	51.5 (7.6)
- high	34 (32)	53.0 (6.0)	28 (22)	54.2 (5.4)
Prosthodontic status; (n (%))				
- dentulous: natural teeth only	44 (40)	54.4 (4.6) a	32 (25)	52.1 (7.2)
- dentulous + partial and/or complete RDPs	22 (20)	50.7 (7.4) ab	36 (29)	52.0 (5.8)
- edentulous; complete RDP in both jaws	43 (39)	49.1 (8.8) b	58 (46)	52.2 (7.1)
Missing teeth; mean (SD)*	10.7 (5.1)		16.8 (8.2)	
Occluding pairs of natural teeth; mean (SD)*	9.4 (3.5)		5.4 (5.0)	
At least one carious tooth; (n (%))*				
- yes	7 (11)	52.5 (5.1)	39 (57)	50.2 (5.8) a
- no	59 (89)	53.2 (6.0)	29 (43)	54.4 (6.6) b
Clinically assessed treatment need; (n (%))				
- yes	40 (37)	48.6 (8.6) a	74 (59)	50.4 (6.2) a
- no	69 (63)	53.3 (6.2) b	52 (41)	54.4 (6.9) b
Self-reported treatment demand (Group A: n=108); (n (%))				
- yes	45 (42)	48.1 (8.2) a	35 (28)	46.2 (7.4) a
- no	63 (58)	54.8 (5.3) b	91 (72)	54.3 (4.9) b
Self-reported general health (Group A: n=107); (n (%))				
- very bad or bad	1 (1)	59.0 (-)	31 (24)	50.6 (7.8)
- moderate	21 (20)	47.6 (4.5) a	40 (32)	52.0 (6.2)
- good	74 (69)	52.0 (6.8) ab	50 (40)	52.8 (6.7)
- very good	11 (10)	55.6 (5.0) b	5 (4)	54.8 (3.9)
Care dependency level; (n (%))	NA	NA		
- 1			26 (21)	52.2 (8.3)
- 2			31 (24)	53.3 (6.5)
- 3			19 (15)	50.1 (8.1)
- 4			29 (23)	53.2 (4.9)
- 6			21 (17)	50.3 (5.7)
SF-12 physical component (PCS); (n (%))	NA	NA		
- Lower than 44.06			104 (83)	52.2 (6.5)
- Higher than 44.06			22 (17)	51.5 (8.1)
SF-12 mental component (MCS); (n (%))	NA	NA		
- Lower than 49.50			62 (49)	51.0 (7.0)
- Higher than 49.50			64 (51)	53.2 (6.4)
Social Support (ESSI) (Group B: n=125); (n (%))	NA	NA		
- low			33 (26)	48.9 (6.5) a
- medium			49 (39)	51.9 (7.4)ab
- high			43 (35)	54.6 (5.0) b

RDP = removable dental prosthesis; Different letters (a,b) indicate significant differences in GOHAI scores (ANOVA and T-tests: Tukey test or Tamhane's test in case of non-homogeneous variances). * Only dentulous subjects.

Perceived general health of care-dependent participants was also worse than that of care-independent participants: 24 % of Group B subjects reported 'bad' or 'very bad' health vs. 1% of Group A subjects, whereas 'good' or 'very good'

general health was reported by 44% of Group B subjects vs. 79% of Group A subjects.

Pearson correlations between GOHAI scores and continuous variables in Group A were: 0.092 ($p=0.340$) for age, -0.387 ($p<0.001$) for number of missing teeth, and 0.362 ($p=0.003$) for number of occluding pairs. In Group B these correlations were 0.104 ($p=0.249$), -0.145 ($p=0.238$) and 0.060 ($p=0.591$) respectively. GOHAI scores for categorical variables are displayed in Table 1.

In Group A, one-way ANOVA and subsequent tests showed that higher GOHAI scores were significantly associated with prosthodontic status (with higher GOHAI scores related to having only natural teeth and lowest to being edentulous with complete RDPs), no clinically assessed treatment need and no self-reported treatment demand, better self-reported general health, lower number of missing teeth, and higher number of occluding pairs. In Group B, the same statistical tests revealed that higher GOHAI scores were significantly associated with absence of carious teeth, no clinically assessed treatment need, and no self-reported treatment demand. Of the health domain variables (physical, mental, social), only (higher) social support scores were significantly associated with higher GOHAI scores (Table 1).

The total number of subjects included in the incremental regression analysis was 107 in Group A (2 subjects had missing data on one of the independent variables) and 126 in group B. Q-Q plots showed no tendencies in the residuals and indicated only minor deviations from normality. For reasons of interpretability of regression outcomes it was therefore decided to use untransformed GOHAI scores. Three regression models were tested to explain the relations between OHRQoL (represented by GOHAI scores) and three sets of variables (Table 2).

Model 1, with background variables age, gender and SES, explained 3.9% of the variance (R^2) in OHRQoL scores in Group A and 1.2 % in Group B. None of these background variables had a significant effect in this model.

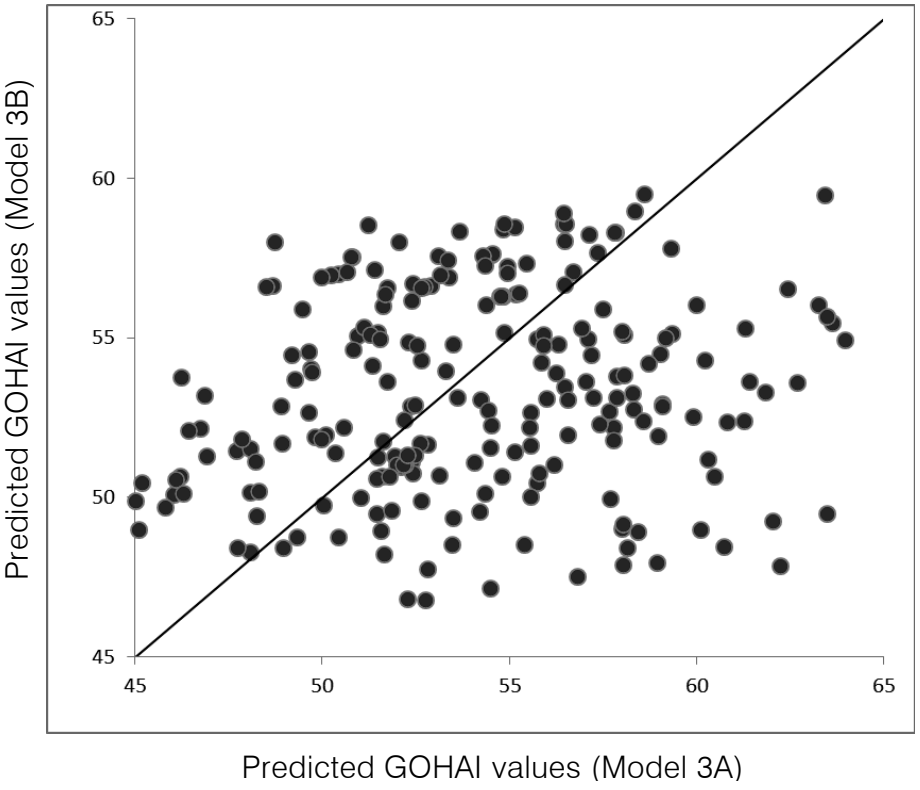
Table 2. Multiple linear regression models for assessing correlation between GOHAI scores and background variables (Model 1), plus oral health variables (Model 2), plus general health variables (Model 3), plus physical health, mental health and social support (Model 4).

	Group A (n = 107)				Group B (n = 126)			
	β	Standar-dized β	P-value	Adjusted R^2		Standar-dized β	P-value	Adjusted R^2
Model 1:		**Model 1A**				**Model 1B**		
- age	0.153	0.108	0.266		0.090	0.095	0.294	
- gender	-2.341	-0.157	0.109		0.634	0.047	0.617	
- SES	1.839	0.171	0.080	0.039	1.428	0.162	0.080	0.012
Model 2:		**Model 2A**				**Model 2B**		
- age	0.325	0.229	0.015		0.053	0.056	0.537	
- gender	-2.418	-0.163	0.074		0.560	0.041	0.649	
- SES	0.374	0.035	0.723		1.501	0.170	0.071	
- prosthodontic status:								
- dentulous + partial and/or one complete RDP(s)	-3.793	-0.206	0.036		-0.014	-0.001	0.993	
- edentulous: complete RDP in upper and lower jaw	-3.184	-0.209	0.089		-2.026	-0.151	0.248	
- carious teeth yes/no	3.082	0.103	0.331		-3.106	-0.214	0.069	
- clinically assessed treatment need	-5.621	-0.364	0.002	0.185	-3.059	-0.225	0.021	0.082
Model 3:		**Model 3A**				**Model 3B**		
- age	0.306	0.215	0.027		0.064	0.068	0.455	
- gender	-2.386	-0.159	0.084		0.401	0.030	0.745	
- SES	0.311	0.028	0.776		1.434	0.163	0.086	
- prosthodontic status:								
- dentulous + partial and/or one complete RDP(s)	-3.607	-0.192	0.053		-0.040	0.003	0.980	
- edentulous: complete RDP in upper and lower jaw	-3.118	-0.203	0.098		-2.207	-0.164	0.208	
- carious teeth yes/no	3.464	0.115	0.280		-2.986	-0.206	0.081	
- clinically assessed treatment need	-5.492	-0.352	0.003		-2.969	-0.218	0.025	
- self-reported general health	1.110	0.084	0.389		0.775	0.100	0.254	
- care-dependency level	NA	NA	NA	0.190	-0.357	-0.089	0.306	0.086
Model 4 (only group B)						**Model 4B**		
- age					0.060	0.063	0.485	
- gender					0.463	0.034	0.705	
- SES					1.393	0.158	0.092	
- prosthodontic status:								
- dentulous + partial and/or one complete RDP(s)					-1.798	-0.134	0.304	
- edentulous: complete RDP in upper and lower jaw					-2.856	-0.197	0.091	
- carious teeth yes/no					-2.376	-0.174	0.078	
- clinically assessed treatment need					0.015	0.018	0.834	
- physical health (SF-12: PCS score)					0.022	0.039	0.654	
- mental health (SF-12: MCS score)					0.190	0.193	0.035	0.102
- social support (ESSI score)								

Dependent: GOHAI score; independent: age (years); gender (male=0, female=1); SES (low=1, medium=2, high=3); prosthodontic status (reference is dentulous without RDP); carious teeth (no=0, yes=1); clinically assessed treatment need (no=0, yes=1); self-reported general health (1=very bad or bad, 2=moderate, 3=good, 4=very good); care-dependency-level (1 (low) to 6 (high)); PCS: physical component summary; MCS: mental component summary; ESSI: Enrichd Social Support Instrument. β: partial regression coefficient

In Model 2, the oral health variables 'prosthodontic status', 'clinically assessed treatment need' and 'at least one carious tooth' were added. The variables (number of) 'missing teeth' and 'occluding pairs of natural teeth' were not included because these variables showed high multicollinearity (VIFs > 10) with the variable 'prosthodontic status'. Model 2 explained 18.5 % (Group A) and 8.2 % (Group B) of the variance. Significant contributing factors to higher GOHAI scores in Group A were: higher age and absence of clinically assessed treatment need, while not having RDPs was nearly significant (p=0.053). In Group B, the only significant factor that contributed to higher GOHAI scores was absence of clinically assessed treatment need, while higher SES and absence of carious teeth were nearly significant.

Figure 1. Scatterplot of paired outcomes of GOHAI values predicted with Model 3A and 3B.



In model 3, self-reported general health and care-dependency (Group B) were added. Although this increased the explained variance to 19.0% in group A and 8.6% in Group B, the effect of better self-reported general health on higher GOHAI scores was small and non-significant.

Using the respective constants and partial regression coefficients of Model 3A (based on Group A data) and Model 3B (based on Group B data), two GOHAI scores (GOHAI A and GOHAI B) were calculated for all 235 participants. Resulting GOHAI A and GOHAI B scores had a mean absolute difference of 4.2 ± 3.1 and showed a low degree of association (Pearson correlation coefficient = 0.20; p=0.002). This low degree of association is visualized in a scatterplot of paired (according to Model 3A and 3B) predicted GOHAI scores that shows no clustering of points along the x=y line (Figure 1).

In Group B, the effects of physical health (PCS score), mental health (MCS score) and social support (ESSI score) were tested in a subsequent model (Model 4, Table 2), in which 125 subjects were included (for 1 subject data on ESSI scores were missing). This model explained 10.2 % of the variance. The only factor that was significantly associated with higher GOHAI scores in this model was higher social support scores; with near-significant associations between GOHAI scores and (higher) SES, (no) carious teeth, and (no) clinically assessed treatment need.

Discussion

This is the first study that examines and compares the patterns of associations between oral health, general health and OHRQoL in two different groups of older people. Results showed that OHRQoL was explained by different factors in groups that differed in care-dependency level and general health, and that the size of associations between separate health domains and GOHAI scores differed: Social support was significantly associated with GOHAI scores whereas physical and mental health were not.

GOHAI scores in the present study were comparable to those found in other studies among older populations in Northwestern Europe [41-44], in which GOHAI scores varied between 46 and 53. The GOHAI scores of care-dependent and care-independent participants were similar despite the notably worse general and oral health conditions of the care-dependent group. This seems to confirm the assumption underlying this study in that care-dependent people cope with and adapt to oral impairments differently resulting in fewer self-reported impacts of such impairments. This phenomenon has been labeled 'disability paradox', which refers to the evidence on frail older people's better self-reported health despite worse health status [7, 13]. Besides, the difference in administration method (questionnaires administered through interviews for care-dependent participants versus self-reported questionnaires for care-independent participants) may have contributed to this difference in GOHAI scores [31].

Regression analysis revealed that, in both groups, self-reported general health was not significantly associated with GOHAI scores, which is contrary to observations in similar studies (e.g. [5, 25, 26]) and partially in line with findings of another study [24]. The absence of significant associations between general health and care-dependency level and GOHAI scores in the present study may be in part explained by the generally high and homogeneous levels of (self-reported) general health in the care-independent group. In the care-dependent group effects of social support may have mitigated the effect of general health or care-dependency level. Other factors that we did not measure may have played a mediating role in the relation between general health and OHRQoL, in particular personality traits (e.g. [28, 45, 46]), and oral health attitudes (e.g. [47-49]), but also dental attendance and oral hygiene habits [50].

In care-dependent older people, social support was found to be much more strongly associated with OHRQoL than physical and mental health, which is in line with a recent study that showed that social support alone explained 19% of the variance in QoL, whereas perceived health status explained only 5% [21]. In a longitudinal study that used structural equation modeling, Gupta *et.al*.

(2015) showed that higher social support scores predicted better OHRQoL through a higher sense of coherence and lower stress levels [45]. It seems that social support induces a coping strategy that allows adults to interpret stressful conditions as being less demanding and that reduces the impacts of being exposed to such conditions [21, 51], and hence modifies both general health and OHRQoL outcomes. Deeper insight into the pathways through which people's social situation, personal traits like coping and adaptation, and environmental factors like being institutionalized modify OHRQoL can best, or perhaps only, be obtained through qualitative research [49, 52, 53].

Although in the present study the variables that were associated with GOHAI scores in the care-dependent and the care-independent groups were different, in both groups clinically assessed treatment need was significantly related to GOHAI scores (Model 3). Oral health, at least to some extent, seems to matter to QoL regardless of care-dependency. Our results indicate that 'clinically assessed treatment need' is a better predictor of GOHAI scores than the more commonly used variables 'caries presence' and 'number of missing teeth'. This can be explained by the fact that it does not comprise only one single oral health status aspect (that may or may not be experienced by its owner), but represents an integrated clinical judgment of overall oral health status. Nevertheless, this variable is rarely used in studies that examine associates of OHRQoL outcomes.

We found no significant contributions to GOHAI scores of the socio-demographic variables age, gender and SES (except for age in independent elders). Studies have shown inconsistent results on this issue; in institutionalized populations, associations often seem to be non-significant (e.g. [24, 54-57]). Because of the limitations set by the inclusion criteria (cognitive alertness, adequate numbers of varying prosthodontic status, care-dependency levels and gender) the sample drawn from RACFs is not entirely representative of care-dependent institutionalized older people; for example the subgroup of dentulous people without RDP(s) is over-represented in our sample. However, there is no reason to expect selection bias within the sampled subgroups. The

care-independent group is expected to largely represent older people who are regular attenders of dental practices, which applies to 66% of the Dutch older population (65-75 yrs old) [58].

Because participation was on a voluntary basis, it can be assumed that, in comparison to the general older Dutch population, our participants have slightly more oral health awareness. Nevertheless, we consider the samples of both care-dependent institutionalized and care-independent home-dwelling people in this study to be representative of the majority of cognitively alert older people in the Netherlands.

This study not only included general health variables, but also distinguished between major health domains which enabled identification of health impacts per domain. In this way, we could identify an effect of social support despite the non-significant contribution of general health variables. However, physical, mental and social health were not measured in the care-independent group. It was expected that outcomes of these health variables would reveal only small differences and hence the number of participants should have been much larger to prove possible effects on OHRQoL. By examining the separate effects of care-dependency level and social support (which is related to being institutionalized [19, 20]) we could gain insight into which of the two factors was more strongly associated with the GOHAI outcomes.

This study underlines the importance of two questions previously posed by Locker e.a. and by Tsakos e.a.: 'What do measures of OHRQoL represent?' [4], and 'How should we interpret OHRQoL data?' [3]. The large differences between OHRQoL associates in care-dependent and care-independent participants may be explained by the fact that the meaning of oral health varies with varying frames of reference [11]. After analyzing 158 qualitative interviews, Krause and Jay (1994) [59] concluded that the specific referents that are used to answer oral health questions vary by age, education and ethnicity. Our results suggest that having social support and being care-dependent are other sources of substantial variation in OHRQoL outcomes. Besides variation in

frames of reference, OHRQoL outcomes are also related to the OHRQoL instrument used (e.g. OHIP, OIDP, GOHAI) [4]. Consequently, the answer to the question on what exactly OHRQoL outcomes represent, depends on the OHRQoL instrument used, individual and population characteristics, and the specific factors that define that population. One may ask whether the name 'OHRQoL' is justified for OHRQoL instruments, especially in aged and vulnerable populations, since OHRQoL outcomes obtained by these instruments seem to be mostly explained by non-oral health variables.

Our results imply that GOHAI outcomes should not be compared across care-dependent and care-independent groups without careful interpretation of these outcomes against the specific factors that distinguish these groups, such as health factors and living environment. Likewise, caution is necessary when using OHRQoL outcomes to measure impacts of oral conditions in epidemiological surveys that comprise different populations. When oral health care strategies are (in part) guided by quantitative OHRQoL outcomes, we suggest that these outcomes should be complemented by information from qualitative studies in order to understand their meaning [60].

Conclusion

GOHAI outcomes have different patterns of association in care-independent and care-dependent older people. In care-dependent people, oral health factors explain less variance in GOHAI outcomes than in care-independent people. In care-dependent people, social support is more strongly related to GOHAI outcomes than oral health factors or other general health factors.

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Chapter 6

Oral health care behavior and frailty-related factors in a care-dependent older population

This chapter is an edited version of the published article: Oral health care behavior and frailty-related factors in a care-dependent older population. Dominique Niesten, Dick Witter, Ewald Bronkhorst, Nico Creugers. *J Dentistry* 2017; doi: 10.1016/j.jdent.2017.04.002. (Epub ahead of print)

Abstract

Objectives: 1. To assess, in older people with different levels of care-dependency, which frailty- and non-frailty related predisposing, enabling and need factors are associated with a) dental service use (DSU) frequency, b) changed DSU after the onset of care-dependency, c) brushing frequency, and d) changed brushing frequency after the onset of care-dependency; 2. To assess if unfavorable oral health care behavior is related to unfavorable oral health outcomes.

Methods: Bivariate analyses and multivariate logistic regression analyses were performed to evaluate data from 126 Dutch care-dependent people aged ≥ 65 on oral and general health, psychological and social issues.

Results: Lower DSU frequency was mainly related to non-frailty-related predisposing factors, especially being edentate (OR=3.75; CI: 1.20-11.71; p=0.023) and lower socioeconomic status (OR=1.74; CI: 0.97-3.14; p=0.065); lower DSU frequency since the onset of care-dependency to frailty-related enabling and need factors, especially 'difficulty going to the dentist' (OR=4.98; CI:1.85-13.36; p=0.001) and clinically assessed treatment need (OR=3.23; CI:1.24-8.42; p=0.016); lower brushing frequency and changed (reduced) brushing frequency to frailty-related enabling factors, and, in case of reduced frequency, significantly to 'not being capable of summoning the effort to brush' (OR=8.28; CI: 1.44-47.56; p=0.018) and high care-dependency level (OR=4.14; CI: 1.05-16.36; p=0.043). Elders with lower and especially those with reduced DSU and brushing frequencies after the onset of care-dependency, had generally worse oral health outcomes and related quality of life.

Conclusions: Oral health care behavior, especially reduced brushing frequency and reduced DSU after the onset of care-dependency, are related to specific frailty-related factors in a care-dependent older population. Oral care-providers should be alert to the role of those factors.

Introduction

Favorable health behavior refers to people's beliefs and actions aimed at avoiding harm, optimizing health and well-being, and preventing diseases [1]. Especially in old age, when people face health decline in the physical, mental and social domains, unfavorable health behavior can have major impacts on health and quality of life. With respect to oral health, poor oral health care behavior, in particular low or no dental service use (DSU) and poor oral self-care, is associated with oral health impairments and reduced oral health-related quality of life [2].

In essence, the main dental diseases, caries and periodontal diseases, are behavioral diseases with bacterial involvement [3], i.e. diseases whose onset and progression can be suppressed by effective oral health care behavior with DSU and brushing frequency of teeth and (partial) dentures as important components. Over the last decade, a number of studies and governmental reports have addressed the deficient oral health of frail and care-dependent older people worldwide [2,4,5]. Older people tend to use dental services less and have lower brushing frequency than younger adults, and these tendencies are even stronger in frail and care-dependent populations [2, 6-10].

Reported barriers to older people's DSU include the lack of self-perceived need for DSU, fear of going to the dentist, (perceived) lack of availability of dental services, characteristics of the dental practitioner, poor health, difficulties in accessing dental services, cost-related factors and impaired cognition [8,11]. Barriers to oral self-care of (institutionalized) older people include the lack of self-perceived need and cooperation of elders, the non-prioritization of care-givers, and impaired mobility, manual dexterity, and cognitive function [2,12,13]. In a qualitative study on frailty-related impacts on oral health care behavior some additional specific frailty-related barriers to DSU and oral self-care were suggested: lack of social support to go to the dentist, difficulty in arranging a dental visit, forgetting to brush teeth or dentures, not being capable of summoning the effort to brush teeth, chronic pain, low energy

level, and deprioritization of oral health [14]. To our knowledge, these barriers have, however, not yet been investigated in relation to DSU and brushing frequency quantitatively and hence are part of the present study.

Studying oral care behavior is important in order to better target and effectively remove barriers to DSU and brushing frequency. This is particularly urgent for vulnerable groups, since these groups face most barriers to health-supporting oral care behavior, which increases the risks for deterioration not only of oral health but also of general health [2]. If care-providers are aware of which (frailty-related) factors are associated with poor oral care behavior, they can undertake due action when they recognize these factors in their patients. Such knowledge will help increase the understanding of mechanisms underlying oral health care behavior of frail older people, and will contribute to cost-effective planning of future oral health care services.

Although there is evidence of a number of possible barriers to DSU and brushing frequency, to our knowledge no studies have documented the extent to which care-dependency level and specific frailty-related factors are related to the oral health care behavior of care-dependent older people. It is unclear which frailty-related factors are associated with brushing frequency, which ones with DSU frequency and which factors are associated with a change in DSU and brushing frequency following the onset of care-dependency.

For some five decades, health behavior models have been developed in order to help understand health care behavior like DSU and brushing frequency. Most commonly used in health research is the (revised) health behavior model by Andersen [15]. This model is based on the assumption that health care behavior practices are largely determined by personal factors that predispose people to use health services (predisposing factors, which include demographic characteristics and health beliefs), factors that enable or impede such use (enabling factors), and people's need for health care (need factors, which include self-perceived and clinically assessed treatment need), and by system-related factors (e.g. insurance system and organization of dental care). System-related factors are, however, assumed to play a marginal role in DSU of

Dutch care-dependent elders, since the health insurance situation and factual availability of dental services have been reported to be near-constant in this subpopulation [16]. Indeed, in a study that included a range of European countries, only 4.6 % of older Dutch people reported system-related factors as a reason for dental non-attendance [17]. Therefore the present study's focus is on personal factors.

Apart from factors in the predisposing, enabling, and need domains, Andersen's model includes a domain 'health outcomes', theorizing that health care behavior affects health outcomes, which comprise self-perceived and clinically assessed health status.

Andersen's model of health care behavior is useful in the evaluation of DSU [10, 18-20] because the distinction between predisposing, enabling and need factors offers clear points of engagement for oral health care improvement strategies and the possible success of such strategies. It is assumed that factors impeding health service use are least mutable in the predisposing domain, whereas factors from the enabling domain are often easiest to alter [15]. The model has also been used, although infrequently, for analysis of health care behavior components like tooth brushing [10, 21]. Baker et. al. found a weak link between DSU and tooth brushing frequency [10] but did not analyze direct relations between tooth brushing frequency and predisposing, enabling or need factors.

Based on the above considerations, we formulated the following study objectives: To assess, in older people with different levels of care-dependency 1) which frailty- and non-frailty related predisposing, enabling and need factors are associated with a) dental service use (DSU) frequency, b) changed DSU after the onset of care-dependency, c) brushing frequency, and d) changed brushing frequency after the onset of care-dependency; and 2) if unfavorable oral health care behavior is related to unfavorable oral health outcomes.

Methods

Population and sample

Participants were recruited from a population of care-dependent people living in randomly chosen residential aged care facilities (RACFs) in South-East Netherlands. Purposive sampling was applied, aimed at achieving adequate numbers of residents with regard to variables whose outcomes were known a-priori and that were expected to influence DSU or brushing frequency (e.g. prosthodontic status (dentate/edentate) and level of care-dependency) [22, 23]. Following instructions by the principal researcher, managers of RACFs asked residents aged 65 and over who were, according to the manager, sufficiently cognitively alert to participate. Details of the sample are described elsewhere [24].

Questionnaire and variables

Self-reported data were obtained using a questionnaire that was administered through a personal interview. Questions not part of a validated questionnaire were pre-tested for comprehensibility and wording by a panel that comprised three senior dental researchers and three care-dependent older people.

The distinction made between frailty-related variables and non-frailty-related variables was based on Gobbens' definition of frailty: 'a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, or social)' [25]. Hence, 11 out of the 18 predisposing factors (including general health), and 7 out of the 8 enabling factors were considered directly frailty-related (FR, see sections below and Table 1, left column). Other variables, such as age and oral health status variables, were considered not or only indirectly frailty-related.

Predisposing factors

Data were collected on age, gender, and socioeconomic status (SES). SES (high/ middle/ low) was determined on the basis of the highest level of either education (high/ middle/ low) or last-held occupation (ISCO-08 classification [26]).

The only oral health variable that was included in the list of predisposing factors was 'prosthodontic status', as assessed by calibrated dental students (more details are provided in the sections 'Need factors' and 'Oral health outcomes' below). Prosthodontic status comprised: dentulous people with at least one natural teeth and without a removable dental prosthesis (RDP), dentulous people with at least one natural tooth and one or more RDPs , and edentulous people with complete RDPs (CRDPs). Edentulous elders who did not wear CRDPs were excluded, since they do not brush dentures or, in general, use dental services.

Perceived general health was assessed using the question: 'How would you rate your general health?' (very bad/ bad/ moderate/ good/ very good). Physical and mental health were assessed through the validated SF-12 (Short Form) health survey [27]. Answers to SF-12 questions were used to compute a physical component summary (PCS) score and a mental component summary (MCS) score (using mean Dutch population-based (70-79 age group) norm scores of 44.06 (PCS) and 49.50 (MCS) [28]). Higher scores indicate better health. Social support was assessed through the validated ENRICHD Social Support Index (ESSI) [29]. The ESSI consists of seven items/ questions scored on a 1-5 point Likert scale; higher scores reflect more social support. Health variables that were considered to be frailty-related were derived from single validated SF-36 [30] or SF-12 questions. Original multi-level answers were dichotomized: suffering from chronic pain (6-level answers dichotomized into yes/no); feeling depressed (6-level into yes/no); energy level (6-level into low/ normal or high); mobility (3-level into good/ moderate or bad); dexterity (3-level into good/ moderate or bad). With regard to care-dependency, we included

participants with care-dependency level 1 (low dependency) through 6 (high dependency) according to the Dutch national care-dependency classification system [31]. In this system, the intensity and type of care needed are regularly determined by a medical authority. People with care-dependency level 5 were excluded since this level comprises predominantly cognitive impairment.

We also included variables indicative of people's beliefs and attitudes to dental health services and oral health, based on the following questions: 'Do you believe that use of dental services helps to maintain or improve your oral health?' (yes/no); 'If you think back to the time before you became care-dependent, which statement applies best to you': 'My oral health is more/ equally/ less important to me now than before the onset of my care-dependency'; 'Do you have fear of going to the dentist?' (yes/no); 'Are you dissatisfied with your current (or most recent) dentist?' (yes/ not applicable/ no); and 'Would you like to use dental services more often than you do now?' (yes/no).

Enabling factors

Specific barriers with regard to DSU were based on the questions: 'Are costs of DSU a barrier to you?' (yes/no); 'Do you have difficulty finding a dentist?' (yes/ not applicable/ no); 'Do you have difficulty arranging a dental visit?' (yes/ not applicable/ no); and 'Do you have difficulty going to the dentist?' (yes/ not applicable/ no). With regard to social support, we constructed the variable 'lack of social support to go to the dentist', which was based on the question: 'In case you need or would need someone's help to go to the dentist, what describes your situation best': lack of support = 'I ask support but no one is able to help me'/ 'There is no one whom I can/ could ask to help me'/ 'I do or would not dare to ask anyone'; no lack of support = 'I do ask and I do get support'/ 'I would ask and I would expect support'/ 'I do or would not ask since dental visits are not important enough to me to ask support for'/ 'I do or would not ask since I do not wish to go to the dentist'.

With regard to brushing behavior, barriers were based on three questions, the first being 'Do you ever forget to brush your teeth or dentures?'((almost) never/ sometimes or often). In case someone indicated that (s)he was assisted by a caregiver in oral hygiene practices, we included the same question regarding the caregiver: 'Does your caregiver ever forget…?' We also asked: 'Do you find it hard to clean your teeth or dentures?' ((almost) never/ sometimes or often); and 'Can you summon the effort to brush your teeth or dentures?'((almost) always/ sometimes or (almost) never).

Need factors

Clinical data were obtained through clinical oral examination according to WHO criteria [32] by final-year calibrated dental students (all κ's > 0.82; overall $\kappa = 0.87$; agreement = 90.1%) and final-year calibrated dental hygiene students (all κ's > 0.66; overall $\kappa = 0.74$; agreement = 84.4%). Data included presence of RDPs or CRDPs (see 'Predisposing factors' above) and clinically assessed treatment need (yes/no), which comprised any need for professional dental treatment, including reline, rebase or replacement of RDPs or CRDPs, and periodontal treatment. The variable 'perceived oral treatment need' was based on the question: 'Do you think you would need any type of oral treatment at the moment?' (yes/no). Furthermore, presence of oral health complaints (yes/no) was assessed through combining the answers to two questions: 'Do you experience pain or discomfort caused by your natural teeth or gums?' and 'Do you experience pain or discomfort caused by your removable or fixed prostheses?' (nearly) always / sometimes/ never or hardly ever). If the answers to both questions were 'never or hardly ever', the presence of oral complaints was set to 'no'; otherwise it was set to 'yes'.

Oral health outcomes

Self-reported oral health outcomes included a question on self-perceived oral health: 'How do you perceive your oral health?' (very bad/ bad/ moderate/

good/ very good) and oral health-related quality of life (OHRQoL), which was measured using the validated Dutch version of the Geriatric Oral Health Assessment Index (GOHAI) [33]. The GOHAI consists of 12 questions on experienced functional and psychosocial impacts of oral health, scored on a 1-5 point Likert scale with higher scores indicating better OHRQoL. Clinically assessed outcomes included number of natural teeth and presence of one or more carious teeth (yes/ no).

Oral health care behavior variables

The variable 'DSU frequency' (DSU Frequency) referred to the self-reported number of visits to a dentist and/or oral hygienist in the past 3 years for all types of professional oral health care such as routine check-up and complaint-based visits, and visits for curative treatment. The variable 'changed dental service use since the onset of care-dependency' (DSU Change) referred to a change of the frequency of (all types of) dental visits. DSU Change was assessed through the question: 'If you think back to the time before you became care-dependent, which statement applies best to you': 'I used dental services about as frequently/ more frequently/ less frequently than I do now'. The variable 'brushing frequency' (Brushing Frequency) referred to the frequency of brushing teeth and/ or cleaning RDPs or CRDPs. The variable 'changed brushing frequency since the onset of care-dependency' (Brushing Change) referred to a change of the frequency of brushing of teeth and/or cleaning RDPs or CRDPs and was assessed through the question: 'If you think back to the time before you became care-dependent, which statement applies best to you': 'I brushed my teeth and/or cleaned my dentures about as frequently/ more frequently/ less frequently than I do now'.

DSU Frequency outcomes were dichotomized into 'higher': for dentates $\geq$ 1 visit per year in the past 3 years, for edentates $\geq$ 1 visit in the past 3 years vs. 'lower': less frequently. DSU Change outcomes were dichotomized into equal or higher vs. lower DSU frequency since the onset of care-dependency.

Brushing Frequency outcomes were dichotomized into 'higher': for dentates ≥ 2 times daily, for dentates with RDP(s) ≥ 2 times daily and ≥ 1 time daily cleaning the RDP(s); for edentates cleaning the CRDPs ≥ 1 time daily vs. 'lower': less frequent. Brushing Change outcomes were dichotomized into equal or higher vs. lower brushing frequency since the onset of care-dependency.

Statistical analysis

In order to assess bivariate associations between the (dependent) oral health care behavior variables DSU Frequency, DSU Change, Brushing Frequency and Brushing Change, and (independent) variables of the predisposing, enabling, and need domains and health outcomes, frequency analyses and univariate logistic regression analyses were performed.

Addressing confounding effects, the associations between dependent variables and independent variables from the predisposing, enabling, and need domains were further examined multivariately using binary logistic regression analysis. This resulted in a model for each dependent variable: DSU Frequency (Model 1), DSU Change (Model 2), Brushing Frequency (Model 3), and Brushing Change (Model 4). Maximal model size was determined for each model, based on the presumption that a minimum of five observations/ participants for each independent variable (based on the least occurring outcome event) is required for outcomes with acceptable accuracy in binary logistic regression [34]. For each dependent variable, the associated independent variables with highest significance levels (lowest p-values, as derived from the univariate logistic regression) were selected up to the number of variables that was allowed, based on the maximal model size.The thus-obtained sets of independent variables were entered in the binary logistic regression analysis in order to construct the four respective models. The predictive efficiency of the resulting models was assessed through calculating percentages of correctly predicted cases and through measurement of the area

under the ROC curve (AUC) of plotted predicted values. SPSS version 22.0 (SPSS Inc., Chicago, IL, USA) was used for all data analyses.

Ethics approval and consent to participate

The study was approved by the Medical Ethics Committee (CMO) of the Radboud University Nijmegen Medical Center (CMO ref. 2012/294). All participants gave informed consent in writing to participate in the study and to publish anonymized results.

Results

General

We included 126 participants in a total of 11 RACFs. The mean age of the participants was 85.4 ± 7.1 years; 73 (58%) were female; and 68 (54%) were dentate, of which 32 (25% of the total) had natural teeth only (Table 1). General health was perceived to be generally good or very good by 55 participants (44%); 29 participants (23%) reported bad health, and 2 (2%) very bad health. Impacts of general health were, however, notably worse than the standardized norms for the age group: the average PCS was 35.7 ± 8.4 (norm score 44.1), and MCS was 47.0 ± 11.8 (norm score 49.5). The level of social support was moderate (mean ESSI score of 22.7 ± 6.6; maximum possible score: 35). The most reported impairments were related to mobility (88%), energy level (68%), dexterity (56%) and chronic pain (35%). Oral health was perceived to be good or very good by 83 participants (66%), which was reflected by a low perceived treatment need (28%), but contrasted with the figures on teeth- or RDP-based complaints (held by 70%), clinically assessed oral treatment need (59%) and the high percentage of dentates with at least one carious tooth (57%) (Table 1).

Bivariate associations (Table 1)

DSU Frequency: most participants (81%) believed that DSU supports oral health, but only 47 (37%) had used dental services 3 or more times (dentates) or at least once (edentates) (Table 1) and 60 participants (48%), of which 41 were edentulous, had made no dental visits at all in the past 3 years (not in table). Although the threshold for 'higher DSU' was lower for edentates i.e. once in 3 years vs. once a year for dentates, the group of participants with lower DSU Frequency comprised more edentates (58%) than dentates. Of the 79 participants with lower DSU Frequency, 42 (53%) said that their DSU frequency was reduced since the onset of care-dependency (not in table). For all participants, the most cited barrier for DSU was 'difficulty going to the dentist' (44%), followed by 'difficulty arranging a dental visit' (23%) and 'difficulty finding a dentist' (14%). Fear of going to the dentist and dental costs (both 12%), being dissatisfied with the dentist (10%), and lack of social support (7%) were less mentioned barriers.

Lower DSU Frequency was significantly associated with higher age, lower SES, being edentate, no belief that DSU supports oral health, being dissatisfied with the (former) dentist, and difficulty finding and going to a dentist. DSU Frequency was not significantly associated with care-dependency level or self-reported general health or with any other general health-related factor, nor with need factors or oral health outcomes except for presence of one or more carious teeth. Although not statistically significant (except for carious teeth), all oral health outcomes were worse for participants with lower DSU Frequency. DSU Frequency was significantly associated with 2, both frailty-related, out of 5 enabling factors, and with 5 out of 18 non-frailty related predisposing factors (Table 1).

Changed dental service use since the onset of care-dependency (DSU Change): 56 participants (44%) reported that their DSU frequency was reduced since the onset of their care-dependency.

Table 1. Characteristics of an institutionalized older care-dependent population (n=126) according to dental service use (DSU) and brushing frequency (BF)

Factors		Total	DSU Frequency: Higher DSU* n=47	DSU Frequency: Lower DSU* n=79	p-value
PREDISPOSING – general					
age (mean, SD)		85.4 (7.1)	83.6 (6.7)	86.4 (7.2)	0.032
gender (% female)		58	51	62	0.229
SES (%)	high	22	36	14	
	middle	40	38	40	0.003
	low	38	26	46	
PREDISPOSING – oral health					
prosthodontic status (%):					
	dentulous: natural teeth only	25	36	19	
	dentulous + partial and/or complete RDPs	29	38	23	0.002
	edentulous: complete RDP(s)	46	26	58	
PREDISPOSING – general health					
care-dependency (FR)(%):	level 1	21	28	18	
	level 2	25	13	31	
	level 3	14	15	14	0.118
	level 4	23	21	24	
	level 6	17	23	13	
perceived general health (FR)(%):	(very) good	44	43	44	0.665
	moderate	32	36	29	
	(very) bad	25	21	27	
SF-12: Physical health (PCS) (FR) (mean, SD)		35.7 (8.4)	35.7 (8.8)	35.8 (8.2)	0.940
SF-12: Mental health (MCS) (FR) (mean, SD)		47.0 (11.8)	46.0 (11.7)	47.6 (11.9)	0.485
ESSI –Social support (FR) (mean, SD)		22.7 (6.6)	23.3 (7.0)	22.1 (6.8)	0.341
chronic pain (FR) (% yes)		35	36	34	0.820
feeling depressed (FR) (% yes)		19	21	18	0.624
energy level (FR) (% low)		68	60	73	0.109
mobility (FR) (% moderate/bad)		88	91	86	0.369
dexterity (FR) (% moderate/bad)		56	45	43	0.857
PREDISPOSING – health beliefs/attitudes					
belief DSU supports oral health (% yes)		81	91	75	0.027
importance of oral health since care-dependency (FR) (% less)		24	23	19	0.554
fear of going to the dentist (% yes)		12	6	15	0.152
dissatisfied with (former) dentist (% yes)		10	2	14	0.059
ENABLING					
DSU costs are a barrier (% yes)		12	6	14	0.196
difficulty finding a dentist (FR) (% yes)		14	4	20	0.025
difficulty arranging a dental visit (FR) (% yes)		23	17	27	0.221
difficulty going to a dentist (FR) (% yes)		44	32	51	0.042
no social support to go to dentist (FR) (% yes)		7	4	8	0.463
forget to brush (FR) (% sometimes/often) (n=121)		27			
find it hard to clean teeth (FR) (% sometimes/often) (n=121)		27			
cannot summon effort to brush (FR) (% sometimes/often)		17			
NEED					
perceived oral treatment need (% yes)		28	21	32	0.211
clinically assessed oral treatment need (% yes)		59	60	58	0.882
teeth- or RDP-based complaints (% yes)		70	74	67	0.384
Oral health outcomes					
GOHAI score (mean, SD)		52.1 (6.7)	52.9 (6.6)	51.2 (6.8)	0.305
perceived oral health (%):	(very) good	66	69	65	
	moderate	22	22	21	0.684
	(very) bad	12	9	14	
dentates only (n=68):			n=34	n=34	
no. of natural teeth (mean, SD)		15.0 (8.0)	16.3 (7.6)	13.6 (8.3)	0.168
caries in ≥ 1 tooth (% yes)		57	46	70	0.048

FR=frailty-related. SES = socioeconomic status; RDP = removable dental prosthesis; GOHAI = Geriatric Oral Health Assessment Index; *Higher DSU Frequency: dentate participants who made ≥1 dental visit per year in the past 3 years or edentate participants who made at least 1 dental visit in the past 3 years; *Lower DSU Frequency: all others; **DSU equal/higher: DSU frequency is equal or higher since the onset of care-dependency; **DSU lower: DSU frequency is lower since the onset of care-dependency; ***Higher BF: for dentates without RDP: BF ≥ 2 times daily; for dentates with RDP(s): BF ≥ 2 times daily and BF of RDP(s) ≥ 1 time daily; for edentates with complete RDPs: BF of RDPs ≥ 1 time daily; Lower BF: all others; ****BF equal/higher: BF is equal or higher since the onset of care-dependency; ****BF lower: BF is lower since the onset of care-dependency. p-values: based on univariate logistic regression analysis.

DSU Change			Brushing Frequency			Brushing Change		
DSU equal /higher** n=70	DSU less** n=56	p-value	Higher BF*** n=85	Lower BF*** n=41	p-value	BF equal/ higher**** n=100	BF less **** n=26	p-value
85.1 (6.6)	85.7 (7.8)	0.613	86.2 (6.9)	83.6 (7.2)	0.056	85.6 (7.0)	84.6 (7.5)	0.538
57	59	0.840	62	44	0.028	61	46	0.175
23	21		21	24		25	12	
41	38	0.826	40	39	0.918	39	42	0.162
36	41		39	37		36	46	
21	30		21	34		23	35	
27	30	0.355	31	24	0.295	29	27	0.470
51	39		48	42		48	38	
21	21		21	22		24	12	
26	23		26	22		24	27	
16	13	0.252	17	10	0.790	17	4	0.021
27	18		21	26		24	19	
10	25		15	20		11	38	
49	38		41	49		42	50	
33	30	0.202	35	24	0.470	35	19	0.311
19	32		24	27		23	31	
37.0 (9.0)	34.2 (7.3)	0.068	35.7 (8.4)	35.7 (8.6)	0.994	36.1 (8.3)	34.4 (8.7)	0.355
47.3 (12.3)	46.7 (11.2)	0.776	48.0 (11.5)	45.0 (12.3)	0.180	47.0 (11.9)	46.9 (11.6)	0.964
24.1 (6.3)	21.0 (6.6)	0.025	23.1 (6.3)	21.9 (7.1)	0.172	22.6 (6.2)	22.1 (9.0)	0.708
33	38	0.587	32	42	0.286	32	46	0.181
19	20	0.879	17	24	0.292	21	12	0.282
60	79	0.028	66	73	0.411	68	69	0.904
87	89	0.712	88	88	0.944	87	92	0.462
56	57	0.872	49	71	0.026	47	31	0.141
86	75	0.132						
16	34	0.019	25	22	0.734	18	31	0.157
6	20	0.023						
4	16	0.036						
9	16	0.203						
9	21	0.047						
19	29	0.188						
24	68	<0.001						
9	5	0.490						
			19	44	0.004	18	54	<0.001
			21	41	0.021	19	58	<0.001
			10	33	0.002	8	50	<0.001
17	41	0.004	28	27	0.869	26	3	0.384
44	77	<0.001	54	68	0.132	57	65	0.440
61	80	0.023	69	71	0.880	69	73	0.687
53.3 (7.1)	50.6 (5.9)	0.025	51.9 (7.2)	52.4 (5.6)	0.710	53.0 (6.1)	48.5 (7.8)	0.005
77	54		70	59		73	42	
17	27	0.017	17	32	0.165	16	42	0.012
6	19		13	10		11	16	
n=34	n=34		n=44	n=24		N=52	N=16	
15.3 (8.3)	14.6 (7.8)	0.703	14.9 (8.0)	15.1 (8.1)	0.948	15.4 (7.7)	13.6 (9.0)	0.111
41	74	0.008	50	71	0.101	52	75	0.424

Forty six percent of this group reported that they wished to visit a dentist more often while 17% in the group with lower DSU frequency in general reported this wish (not in table). In comparison to participants with equal or higher DSU, the group with reduced DSU reported more barriers to DSU, in particular ‘difficulty going to a dentist’, (68%), and had significantly higher perceived treatment need (41%), clinically assessed treatment need (77%), and more teeth- or RDP-

based complaints (80%) (Table 1). The oral health outcomes of this group were significantly worse than for those with equal or higher DSU frequency: mean GOHAI score was 50.6 ± 5.9 vs.53.3 ± 7.1 (p=0.025); moderate or (very) bad self-rated oral health was 46% vs. 23% (p=0.017); and 74% vs.41% (p=0.008) of the dentate participants had at least one carious tooth.

Reduced DSU frequency since the onset of care-dependency was significantly associated with lower social support (ESSI), low energy level, less importance attached to oral health, fear of going to the dentist, being dissatisfied with the dentist, difficulty finding and difficulty going to a dentist. Reduced DSU frequency was also significantly associated with need and oral health-related outcomes: higher perceived treatment need, higher clinically assessed oral treatment need and more teeth- or RDP-based complaints, lower GOHAI scores (lower OHRQoL), and impaired perceived oral health. Although not significantly, reduced DSU frequency was prevalent in participants with lower SF-12 physical and mental health scores, and in participants without belief that DSU supports oral health. DSU Change was significantly associated with 3 out of 3 need factors, 2 (both frailty-related) out of 5 enabling factors, and 5 out of 18 predisposing factors, of which 2 (energy level and social support) were frailty-related (Table 1).

Brushing Frequency: 85 participants (67%) brushed their teeth at least twice daily and cleaned their dentures, if present, at least once daily (Table 1). Lower brushing frequency was significantly associated with being male (56%), impaired dexterity (71%) and with the barriers 'finding it hard to clean teeth' (44%), 'forgetting to brush' (41%), and not being capable of summoning the effort to brush (33%) (Table 1). Brushing frequency was significantly associated with 3 out of 3 enabling factors, and with 2 (dexterity and gender) out of 15 predisposing factors, but not with any need factors or oral health outcomes. Four of the 5 significantly related factors were frailty-related (Table 1).

Changed brushing frequency since the onset of care-dependency (Brushing Change): 26 participants (21%) reported that their brushing frequency was reduced since the onset of their care-dependency. Reduced brushing

frequency was significantly associated with a high level of care-dependency, forgetting to brush (54%), finding it hard to clean teeth (58%), and not being capable of summoning the effort to brush (50%). Self-perceived oral health outcomes of the group with reduced brushing frequency were significantly worse than for those with equal or higher brushing frequency: mean GOHAI score was 48.5 ± 7.8 vs.53.0 ± 6.1 (p=0.005); moderate or (very) bad self-rated oral health was 58% vs. 27% (p=0.012). Brushing Change was significantly associated with 1 out of 15 predisposing factors and 3 out of 3 enabling factors, all frailty-related (Table 1).

Multivariate associations: binary logistic regression models (Table 2)

Maximum model size confined maximum numbers of independent variables to 9 (47/5; Model 1), 11 (56/5; Model 2), 8 (41/5; Model 3), and 5 (26/5; Model 4) respectively. In order to not exceed the maximum number of 5 independent variables in Model 4, we recoded the five-level variable 'care-dependency level' into a three level variable ('low': levels 1 and 2; 'medium': levels 3 and 4; 'high': level 6).

Frequency of dental visits (DSU Frequency, Model 1): the only significant factor associated with lower frequency of dental visits that held its significance was prosthodontic status (a non-frailty-related predisposing factor). Edentates had an almost four times (OR=3.75, p=0.023) higher chance of having lower DSU than dentates with or without RDP(s). Another non-frailty-related predisposing factor, SES, was near-significant (OR=1.74, p=0.065). Changed dental service use after the onset of care-dependency (DSU Change, Model 2): 'difficulty going to the dentist' (OR=4.98, p=0.001) (a frailty-related enabling factor) and presence of a clinically assessed treatment need (OR=3.23, p=0.016) (need factor) were significantly associated with less DSU after the onset of care-dependency.

Table 2. Binary logistic regression models for assessing correlation between preselected* variables and: Frequency of dental service use (DSU Frequency) (Model 1); Change in dental service use (DSU Change) (Model 2); Brushing Frequency (Model 3), and Change in brushing frequency (Brushing Change) (Model 4) in an older care-dependent population (n=126)

Variable	OR	CI (95%)	P-value
Model 1: DSU Frequency			
age	1.05	0.98-1.12	0.154
SES	1.74	0.97-3.14	0.065
dentulous with RDP(s)	0.93	0.31-2.85	0.903
edentulous with complete RDPs	**3.75**	**1.20-11.71**	**0.023**
energy level (FR)	1.07	0.41-2.80	0.883
no belief DSU supports oral health (FR)	1.63	0.41-6.53	0.490
dissatisfied with dentist	6.75	0.72-63.77	0.096
difficulty finding a dentist (FR)	3.60	0.63-20.70	0.151
difficulty going to a dentist (FR)	1.64	0.59-4.58	0.347
Model 2: DSU Change			
Physical Component Score (PCS) (FR)	0.96	0.91-1.02	0.202
social support (ESSI) (FR)	0.97	0.91-1.04	0.417
energy level (FR)	1.39	0.52-3.74	0.512
importance of OH since care-dependency (FR)	1.57	0.49-5.01	0.449
fear of going to dentist	1.54	0.33-7.09	0.582
dissatisfied with dentist	2.43	0.52-11.37	0.259
difficulty finding a dentist (FR)	1.85	0.49-6.90	0.362
difficulty going to a dentist (FR)	**4.98**	**1.85-13.36**	**0.001**
perceived treatment need	1.88	0.64-5.53	0.255
clinically assessed treatment need	**3.23**	**1.24-8.42**	**0.016**
teeth- or RDP-based complaints	2.19	0.81-5.96	0.125
*Model 3: Brushing Frequency***			
age	0.95	0.90-1.02	0.147
gender	0.50	0.20-1.22	0.126
social support (ESSI) (FR)	0.96	0.90-1.03	0.272
dexterity (FR)	2.09	0.78-5.59	0.142
forget to brush (FR)	1.36	0.34-5.22	0.652
find it hard to clean teeth (FR)	1.15	0.39-3.43	0.797
cannot summon effort to brush (FR)	3.49	0.80-15.30	0.097
clinically assessed treatment need	1.34	0.52-3.45	0.539
*Model 4: Brushing Change***			
care dependency-level medium (FR)	0.50	0.13-1.91	0.313
care dependency level high (FR)	**4.14**	**1.05-16.36**	**0.043**
forget to brush (FR)	1.25	0.23-6.91	0.795
find it hard to clean teeth (FR)	2.46	0.73-8.24	0.145
cannot summon effort to brush (FR)	**8.28**	**1.44-47.56**	**0.018**

Model 1: correctly predicted cases = 74.6%. AUC = 0.807 (0.729-0.884).
Model 2: correctly predicted cases = 74.6%. AUC = 0.824 (0.753-0.895).
Model 3: correctly predicted cases = 70.8%. AUC = 0.759 (0.672-0.846).
Model 4: correctly predicted cases = 85.0%. AUC = 0.800 (0.682-0.918).
*preselected: based on lowest p-values in univariate logistic binary regression analysis on outcome variable. **n=121 (5 answers missing in variables 'find it hard to clean teeth' and 'forget to brush').
FR=frailty-related. OR=Odds-ratios; CI= 95% confidence intervals; SES = socioeconomic status; RDP = removable dental prosthesis; ESSI = Enrichd Social Support Instrument.
Dependent variables: Model 1: DSU Frequency: 0=dentate participants who made ≥1 dental visit per year in the past 3 years or edentate participants who made at least 1 dental visit in the past 3 years; 1=all others (lower DSU). Model 2: DSU Change: 0=DSU frequency is equal or higher since the onset of care-dependency; 1=DSU frequency is lower. Model 3: Brushing Frequency (BF): 0=for dentates without RDP: BF ≥ 2 times daily; for dentates with RDP: BF ≥ 2 times daily and BF of RDP(s) ≥ 1 time daily; for edentates with complete RDPs: BF of RDPs ≥ 1 time daily; 1=all others (lower BF). Model 4: Brushing Change: 0=Brushing frequency is equal or higher since the onset of care-dependency; 1=Brushing frequency is lower.
Independent variables: age (years); SES: 1=high, 2=middle, 3=low; belief DSU supports oral health: 0=yes, 1=no; difficulty finding a dentist: 0=no/not applicable, 1=yes; difficulty going to a dentist: 0=no/not applicable, 1=yes; dissatisfied with dentist: 0=no/not applicable, 1=yes; energy level: 0=high or normal, 1=low; prosthodontic status: reference is dentate without RDP; PCS: higher scores indicate better health; ESSI: higher scores indicate more social support; dental fear: 0=no, 1=yes; importance of OH since care-dependency: 0=equally or more important, 1=less important; clinically assessed treatment need:0=no, 1=yes; perceived oral treatment need: 0=no, 1=yes;

teeth- or RDP-based complaints: 0=no, 1=yes; gender: 0=male, 1=female; dexterity: 0=good, 1= moderate/bad; forget to brush: 0= (almost) never, 1=sometimes or often; hard to clean teeth: 0= (almost) never, 1=sometimes or often; cannot summon effort to brush: 0=(almost) never, 1=sometimes or often; care dependency level: 0=low (levels 1 and 2), 1=medium (levels 3 and 4), 2=high (level 6).

Brushing frequency (Brushing Frequency, Model 3): no variables were significantly associated with brushing frequency. The variable 'cannot summon the effort to brush' (a frailty-related enabling factor) showed the strongest association with lower brushing frequency (OR=3.49; p=0.097).

Changed brushing frequency after the onset of care-dependency (Brushing Change, Model 4): high care-dependency (OR=4.14, p=0.043) and 'cannot summon the effort to brush' (OR=8.28, p=0.018) were significantly associated with reduced brushing frequency.

The predictive efficiency of Models 1, 2 and 4 were good and that of Model 3 fair, as indicated by respective AUCs of 0.807 , 0.824 , 0.800, and 0.759, and percentages of correctly predicted cases of 75%, 75%, 85% and 71% (Table 2).

Discussion

This is the first study that investigates the associations between oral health care behavior outcomes and predisposing, enabling, and need factors in a population of care-dependent Dutch elderly, thereby distinguishing between frailty- and non-frailty-related factors.

Although only reduced brushing frequency since the onset of care-dependency was significantly associated with the global measure 'level of care-dependency', we found significant bivariate associations with separate frailty-related factors. These were mainly energy level (DSU Change), dexterity (Brushing Frequency), and a number of frailty-related barriers, of which difficulty going to the dentist (DSU) and inability to summon the effort to brush (Brushing Frequency) were the most important. With respect to oral health care behavior, these findings emphasize the importance of studying components of frailty separately rather than through global measures such as a frailty- or care-

dependency index. The current study demonstrated the different association patterns for different oral health behavior variables. While brushing frequency was mainly related to enabling frailty-related factors, the frequency of DSU was mainly related to predisposing factors that were not frailty-related. Our findings suggest that the evidenced importance of predisposing factors, in particular prosthodontic status and SES, as a predictor for DSU in older populations (e.g. [17, 35, 36]) also applies to care-dependent populations. In contrast to DSU Frequency, reduced DSU since the onset of care-dependency was mainly related to need and frailty-related enabling factors. Although causality cannot be established in a cross-sectional study, it is likely that people who make less use of dental services after the onset of care-dependency, which applied to 44% of our participants, do so for a variety of frailty-related reasons. These include a worsened social support situation and lower energy level but also a less favorable oral health attitude. Indeed, the suggestion that especially oral health attitudes play an important role in oral health care behavior [14, 37] was supported by this study in that 'being dissatisfied with the dentist', lower 'importance of oral health since the onset of care-dependency' and 'fear of going to the dentist' were all significantly related to reduced DSU since the onset of care-dependency in the bivariate analyses while lower DSU was significantly associated with 'lack of belief that DSU supports oral health' and near-significantly ($p=0.057$) with 'being dissatisfied with the dentist'.

Despite the high proportion of people with lower DSU in combination with high clinically assessed oral treatment need and oral complaints, most barriers to DSU were reported by less than 20% of the participants. The majority of people with lower DSU stated that they did not wish to go more often. This finding has also been reported by others (e.g. [38]) and could in part be explained by coping mechanisms that play a modifying role in oral health behavior in older populations [39, 40]. Besides, apart from adapting to oral discomfort, part of the population of severely frail older people tends to purposely use their energy for more attainable and rewarding goals than preserving good oral health [14].

Difficulty in going to the dentist, as reported by 44% of participants in this study, or likewise access-related barriers are reported worldwide as a reason for not using dental services [9]. However, previous qualitative research demonstrated that substantial variety is found across individuals in what exactly these difficulties entail, e.g. difficult access to the practice or transport- or mobility-related barriers [14]. In order to increase DSU, it would be worthwhile to explore this quantitatively, and find out to what extent specific difficulties are a decisive barrier for DSU.

There are limitations to this study. First, our study sample is not entirely representative of care-dependent institutionalized older people in Dutch RACFs because of the limitations set by the inclusion criteria (e.g. cognitive alertness and adequate numbers of dentates and edentates), as discussed in a previous study that used this sample [24]. Nonetheless, we consider the sample to be representative of the majority of cognitively alert institutionalized older people in the Netherlands. Second, since we were predominantly interested in finding covariates for oral health care behavior within a cross-sectional dataset, this study focused on relationships between oral health care behavior and factors from the Andersen domains, and not on the relationships between factors across the domains, nor could any directions of found relationships (causality) be established. It can be assumed that some of the found associations were a partial result of the relations between domain factors. For example, people of low SES are expected to more often experience cost barriers. Third, outcome measures, and most independent variables, were self-reported, which introduced a degree of social-desirability- and memory bias, e.g. the real frequencies of DSU and brushing are most likely to be somewhat lower than reported. This leads to an estimated small, yet inevitable, degree of inaccuracy. Fourth, only the frequency of tooth- and denture brushing was used as a measure for oral hygiene behavior. Other hygiene practices such as interdental cleaning were not taken into account. Nevertheless, since tooth brushing is a key self-care strategy for oral health [41], we considered brushing frequency as a valid indicator of oral hygiene behavior. Fifth, the included number of

subjects, although sufficient to justify the performed analyses, was not large and sets limits to the robustness of the results.

Our study indicated that the majority of the studied population used dental services infrequently and 48% had not used any dental services at all in the last three years. The Dutch practice guideline on DSU for frail elderly recommends that the frequency of dental control visits be flexible and personalized according to a person's oral health risk profile [42]. The unfavorable oral health outcomes of the studied population, and especially in people with lower DSU since the onset of care-dependency, support the assumption that the DSU of the majority of participants is inadequate for maintaining or achieving favorable oral health.

The reported barriers to brushing (forgetting to brush, not being able to summon the effort or finding it hard to clean teeth) indicate that daily support with tooth brushing should be made available for care-dependent elders. This may reduce the high caries incidence found in the dentate groups with lower (71%) and reduced brushing frequencies (75%), and also lead to more favorable self-perceived oral health of people with reduced brushing frequency.

One somewhat remarkable finding was that lower DSU and lower brushing frequency were not significantly associated with unfavorable oral health outcomes (apart from presence of one or more carious teeth) and presence of complaints and a treatment need, whereas reduced DSU and reduced brushing frequency since the onset of care-dependency, were. This suggests that the groups that arguably deserve most attention and that should be the first priority of oral health and oral health care improvement strategies are those comprising of people who have changed their oral health care behavior through reduction of DSU and/or brushing frequency. These respective groups are characterized by, besides their unfavorable oral health outcomes, a higher level of care-dependency and more experienced barriers to favorable oral hygiene behavior (reduced brushing frequency) and by a high presence of treatment needs, low level of energy, lack of social support, attitudinal barriers, difficulty going to and finding a dentist, and by being

dissatisfied with their (former) dentist (reduced DSU frequency). This found importance of the role of the dentist should alert dentists to the fact that their patients' past experiences influence their future behavioral intentions, as was recently addressed by Schneider e.a. [43].

The number of significantly related factors in the regression analyses was low. This could indicate that important variables were not sampled, or, more likely given the good predictive efficiency of the models, it demonstrates how complex oral health care behavior of frail institutionalized older people is. Hence, a personalized care approach with alertness to the potentially negative effects of frailty factors is needed. This approach should especially target those frailty factors that have to do with motivation (e.g. energy, ability to summon the effort to brush) and that enhance ease of going to the dentist.

In order to be able to recognize or estimate the risk of frailty factors accurately, dentists should explore the general physical, mental, and social health conditions and medications of their older patients profoundly and record these in an oral health care plan. When doing so, they may have to invest in acquiring additional adequate knowledge of geriatric health. In turn, physicians should document and share information on frailty with dentists and dental hygienists, nurses, and informal carers.

Finally, policy makers should aim at strategies that take the variety of reasons for dental non-attendance and for unfavorable oral hygiene behavior, into account. Elders at highest risk for adverse oral health outcomes (in our study the groups with reduced DSU and reduced brushing frequency since the onset of care-dependency) seem to have altered their oral health care behavior mostly because of frailty-related 'enabling' reasons, which, according to Andersen's theory, are less difficult to address than predisposing and need factors. Admittedly, it may be hard to alter DSU frequency in general since it largely depends on prosthodontic status and SES and corresponding oral health care routines established earlier in life [18, 44]. However the reduction in DSU and in brushing frequency after the onset of care-dependency can

possible be mitigated by removing barriers for making dental visits and upkeep of oral hygiene.

Conclusion

The institutionalized care-dependent residents in this study had less than good oral health while their frequency of DSU was low. This frequency was mainly related to non-frailty-related predisposing factors, of which prosthodontic status and SES were the most important. Reduced dental service use since the onset of care-dependency, in contrast, was mainly associated with frailty-related enabling factors and with need factors, of which 'difficulty going to the dentist' and 'clinically assessed treatment need' were the most important. Both brushing frequency and reduced brushing frequency since the onset of care-dependency were mainly related to frailty-related enabling factors, of which 'being capable of summoning the effort to brush' was the most important; Elders with lower (vs higher) and especially those with reduced DSU and brushing frequencies (vs. equal/higher), had generally worse oral health outcomes and related quality of life. Care providers should be alert to the potentially negative effects of specific frailty-related components on oral health care behavior.

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Chapter 7

General Discussion

Introduction

The five studies presented in this thesis yield detailed information regarding the overall objectives of our study. With two qualitative studies, we gained new insights into older people's experiences, perceptions, and attitudes with regard to oral health; received oral health care; barriers to obtaining oral health care; and oral health-related quality of life. The relations between oral health care behavior, oral health outcomes, oral health needs, and frailty-related factors that were identified through qualitative research were partly confirmed in our subsequent quantitative studies. Integrated key results are discussed below and placed in the context of the current academic discourse on and developments in oral health care for frail elders in The Netherlands.

Experiences, perceptions, and attitudes

Turning points and motivation

One of our main findings is that oral health care behavior of frail and care-dependent elders can, in large part, be explained by their motivation, and that with increasing frailty there seems to be a turning point where people give up their usual oral health care behavior and caring about preservation of natural teeth. Other studies have also indicated that motivation is a key predictor of oral health care behavior (e.g. [1-5]) and is in itself influenced by number of natural teeth [2, 6].

Linked to this turning point in motivation, a turning point with regard to importance attached to oral health may also explain the phenomenon of less experienced negative impacts of oral health impairments in care-dependent versus care-independent older people. This phenomenon was illustrated by similar GOHAI (Geriatric Oral Health Assessment Index) scores in both groups despite notably worse oral health conditions in care-dependent people (Chapters 4 and 5). Although this could be partly due to differences in the methods of administering the GOHAI questionnaire and hence underreporting of negative impacts in the interviews with care-dependent participants [7] (as

discussed below, page 155), it is likely that the effects of coping and adaptation (Chapter 1 and 2) add to this phenomenon. Frail older people's oral health and its impacts are clearly experienced against the background of declining health (Chapter 3 and [8]). Coping and adaptation processes guide perceived oral health needs and, according to Brondani and MacEntee [9], are able not only to mitigate but even to reverse the experience of negative impacts of oral health.

Indicative of the motivation for care-seeking behavior is perceived need [10]. In our studies (Chapters 5 and 6), only 28% of the care-dependent respondents perceived a need for treatment, although 59% had a clinically assessed treatment need and 70% reported oral complaints. These numbers agree with figures from international studies on this topic [11-15]. In other words, people recognize oral discomfort and report complaints, but do not make the translation from discomfort to acknowledging that there is a problem, and that dental service use may help solve it. This may be partly explained by their lack of belief that dental service use can help maintain or improve oral health (reported by 25% of people with low dental service use frequency, Chapter 6). More importantly, these discrepancies can be explained by the reduced importance attached to oral health following the onset of care-dependency (Chapters 3 and 6), a deliberate weighing of perceived efforts against benefits of dental service use (Chapter 3), and the effects of coping and adaptation to discomforts (Chapters 2 and 3).

Improving motivation

One of the current Dutch oral health improvement strategies is aimed at increasing the number of regular check-up visits of frail elderly [16]. In the case of a demotivated person, however, this lack of motivation needs to be addressed first. Enhancing motivation to engage in favorable (general) health care behavior has been proven to improve health outcomes [17, 18]. But to what extent demotivated frail older patients can be motivated to engage in favorable oral health care behavior remains to be researched. The question of

how and to what extent efforts should be undertaken to this end is in part an ethical issue, the answer to which depends on what oral health status is viewed as 'acceptable', in the context of the frail person's situation, by dental professionals. People who belong to the, in Schmidt's words [19], 'leave me alone' group (in response to efforts to engage them in preventive health care programs) may feel patronized by such efforts or might judge the required input to be too burdensome. The existence of such a group within our study population was inferred not only from the findings of our qualitative study (Chapter 3) but also from the large group (83%) of people with low dental service use that did not wish to see a dental professional more often (Chapter 6).

Motivation, self-esteem, and oral health

Up to the (turning) point where people were severely burdened by health impairments, the preservation of natural teeth and adherence to previously established oral hygiene routines was found to add to self-esteem (Chapters 2 and 3). While the link between self-esteem and (self-perceived) oral health has been established by several authors (e.g. [20-23]), the direction of this link is not clear from these studies. Locker [21] argues that it is most likely that poor self-esteem causes poor self-perceived oral health. Our results show that the link can also point in the other direction: good self-perceived oral health, in particular having one's own teeth in old age, makes people proud and is therefore likely to contribute positively to self-esteem. As a consequence, a desire to maintain or increase one's self-esteem may motivate people to improve their oral care behavior. A similar mechanism has been suggested for health and health care behavior in general: self-esteem may enhance outcomes of interventions geared at improving the health behavior of marginalized groups [24] or act as a motivator to improving physical health [25].

Received oral health care and barriers

Oral health and oral health care outcomes

Our study results add to the evidence of poor oral health and low dental service use of frail Dutch elders. Figures on caries prevalence (in 57% of the dentates), clinically assessed treatment needs, and oral complaints (in respectively 59% and 70% of the study population) (Chapters 5 and 6) resemble those found by Hoeksema [26] in a frail Dutch population. Likewise, our low dental service use figures (only 37% used dental services at least once a year (dentates) or at least once every 3 years (edentates)) resemble dental service use data provided by national insurance companies [27]. According to national insurance data, 43,8% of Dutch elders (70-80 yrs; dentates and edentates, ratio dentates/edentates not provided) visited a dentist at least once in 2015. It should be stressed that the low dental service use frequency found in our study was despite our using a most conservative threshold for 'higher' dental service use of at least once a year for dentulous and once every 3 years for edentulous elders. If we had used a threshold value of at least twice a year, as some dental professionals recommend and which seems justified by the generally poor oral health outcomes of this group, notably fewer people than the found 37% would have had 'higher' dental service use frequency.

Oral health care pathways

In order to understand dental service use of frail and care-dependent elderly, it is important to explore pathways of interlinked factors that increase or decrease people's dental service use [28, 29]. On the basis of findings from our qualitative study (Chapter 3), we could summarize some of these pathways as follows: *1. Chronic pain, low energy level and low morale (feeling depressed) mainly affect oral health care behavior through devaluation of oral health importance and by reducing motivation; 2. Physical constraints reduce self-efficacy beliefs with regard to oral hygiene practices; 3. Bad past experiences, often in combination with reduced motivation, affect outcome expectations with regard to dental visits; 4. Lack of social*

support, impaired mobility and dexterity, failing memory, and disorientation can constitute structural external barriers to oral care behavior.

Our quantitative analysis (Chapter 6) confirmed some of the above associations at significance level in the bivariate analyses: 1. Motivation-related factors (low energy, finding oral health less important since the onset of care-dependency, not being able to summon the effort to brush teeth) were significantly associated with reduced dental service use after the onset of care-dependency and/or with lower or reduced brushing frequency; 2. Impaired dexterity and 'finding it hard to clean teeth' were significantly associated with lower brushing frequency; 3. Bad past experiences (being dissatisfied with the (former) dentist), lack of belief that dental service use supports oral health and finding oral health less important since the onset of care-dependency, were all significantly associated with lower dental service use; 4. Low social support, difficulty finding a dentist (associated with reduced dental service use), and impaired dexterity and forgetting to brush (associated with lower brushing frequency) were significantly associated with adverse oral health care behavior.

Access to oral health care

'Difficulty finding a dentist' is more likely to be due to disorientation (Chapter 3) or *perceived* lack of availability [30] than to factual low availability of dentists in The Netherlands [27], where availability is generally seen as sufficient. However, Dutch dentists [31], just like dentists worldwide [32], have been reported to experience barriers to providing oral health care to frail older people, such as a lack of specific knowledge and skills, inadequate circumstances for performing oral examinations and dental treatments, and poor reimbursement when making home- or care-home visits. These barriers may reduce their availability for delivering oral health care to frail older people.

Surprisingly, while 'difficulty going to the dentist' was significantly related to reduced dental service use even in the multivariate regression analysis, mobility was similar in the groups with reduced dental service use and without reduced dental

service use (Chapter 6). We therefore hypothesize that the reported difficulty with going to the dentist in our population is not a consequence of mere physical constraints or limited factual accessibility, but rather of the perception that going to the dentist requires (too) much effort. In order to test these pathways, the direction or causal links between found associates will have to be established in longitudinal studies.

Indeed, in the words of McIntyre *et.al*. [33], "access to health care represents the empowerment of an individual to use health care and reflects an individual's capacity to benefit from services given the individual's circumstances and experiences in relation to the health care system". Hence, even with equal access to oral health care services, differences in the use of these services, as shown in Chapter 6, can arise as a consequence of individual differences in empowerment, which are constituted by, among other things, the belief that dental service use can help improve oral health; social support; satisfaction with the (former) dentist; and perceived ease of going to the dentist. Increasing use of oral health services thus entails a responsibility for decision makers actively to empower individuals to use those services when required.

GOHAI and measuring oral health-related quality of life

Although the GOHAI-NL (Geriatric Oral Health Assessment Index for The Netherlands) was found to be an instrument (a questionnaire) with sufficient validity and reliability to measure oral health-related quality of life (OHRQoL) (Chapter 4), our study also revealed some limitations of the instrument. The use of dimensions within the scale is questionable, as they showed large ceiling effects and had only moderate or even low (in the care-dependent group) correlations with the overall scale, especially the dimension 'pain and discomfort'. We also found that the GOHAI was associated with largely different sets of variables in the two populations of care-dependent and care-independent people (Chapter 5). The clinical relevance of this finding lies in the

light that it throws on the ubiquitous use of OHRQoL outcomes as measured with instruments such as the GOHAI. Our findings indicate that OHRQoL outcomes should not be compared across notably different populations without knowing the contextual factors that influence OHRQoL within such populations.

Our findings confirm the suggestion made by Locker and Allen [34, 35] that what is being measured by OHRQoL instruments is not exactly clear. These instruments document the frequency of experienced functional and psychosocial impacts of oral disorders and as such are useful at population level. They do not, however, provide information on the meaning and significance of those impacts. After all, the way people conceive (oral) health and related quality of life varies according to the social, cultural, political, and practical contexts in which the concepts are being operationalized and measured. As such, perceptions of health and quality of life necessarily involve personal and social judgments about what is normal or worthwhile and are therefore largely influenced by personal, cultural, and societal values [36-38]. Such values, as shown by others [39, 40] and, with regard to personal values, in our studies (Chapters 2 and 3), are not consistent over time and are affected by general health decline. In other words: when assessing quality of life, one should always beware of the tentative character of the answers one receives.

This limitation of quality of life research is likely to have a stronger impact when quality of life questionnaires are used than when open-ended questions or semi-structured interviews are applied. In the latter case, respondents usually provide enough context for a reliable interpretation of their answers. It follows that findings obtained from OHRQoL instruments like the GOHAI should be supplemented with contextual information that can best be derived through qualitative methods, since the answers to OHRQoL questions are highly context-dependent, both within and across subjects (Chapters 2 and 3) and (sub-) populations (Chapters 4 and 5).

Study design

Qualitative research

Since the quality of life of people with severely impaired health conditions is "the product of an interaction between impairment and disability, their personal characteristics, and the physical and social environments in which they live" [41], these complex interactions cannot be detected or understood through mere quantitative tests. The same applies to these people's oral health care behavior [42-44]. The interpretative restrictions that the use of the GOHAI imposes (Chapters 4 and 5) are only one example of the need for qualitative information when one wishes to understand how frail and care-dependent people experience oral health. Using quantitative research to supplement qualitative studies, as undertaken in this thesis, "enhances the generalizability and clinical relevance of the findings and produces detailed, contextualized, and rich answers to research questions that would be unachievable through quantitative or qualitative methods alone", as Shneerson and Gale state [45]. The information derived from our qualitative studies was important for formulating relevant questions that were used in the quantitative studies. Besides, the qualitative studies yielded detailed information and context for interpretation of the findings of our quantitative studies. The added value of qualitative research for dentists is addressed in more detail in Annex 2.

Included participants and variables

Our inclusion criteria and selection and construction of variables had several main consequences for the interpretation of our findings.

First, cognitively impaired elders were not included. Yet we included as participants three recipients of care-level package (CLP) 5 in our qualitative studies despite the fact that CLP 5 generally comprises serious cognitive impairment. This is explained by the referral of care managers, who judged the mental state of these particular CLP 5 participants to be adequate for interviewing, which proved to be the case. Given the documented associations

between poor cognition and oral health-related variables (e.g. [46-54]), our results might be expected to overestimate positive outcomes of OHRQoL, oral health variables and oral health care behavior of frail older people in general.

Second, selection bias as a result of voluntary participation of respondents who most likely have more positive health attitudes and better oral health than average [55], as well as the social desirability of answers and memory bias [56], tend generally to add to the above-mentioned overestimation of positive outcomes.

Third, the difference in the method of administering the questionnaires for care-independent and care-dependent participants (i.e. self-reported vs. personal interview) (Chapters 4 and 5) could potentially influence the answers [57], although the size of this influence is not known for GOHAI scores and oral health status. Personal interviews are expected to result in an underestimation of negative effects for questions affected by social desirability [58], although it is expected to be less of a problem for oral health assessments than for assessments in the psychological and social sciences [59]. As an illustration of this point, Reissmann *et.al.* [7] found that the component of Oral Health Impact Profile (OHIP) score variance explained by the method of administration was very small (0.5%) in comparison to the component explained by individual differences (90%).

Fourth, oral health was covered by clinically assessed overall oral treatment need (including prosthetic and periodontal needs), untreated caries, number of natural teeth and occluding pairs of teeth, and self-reported oral health. It did not include a separate clinical assessment of periodontal status or less common disorders (e.g. temporomandibular joint disorders or oral cancer). A recent study by Masood *et.al*. among 1277 elderly people showed that periodontal status was not related to OHRQoL but that caries, wearing dentures and the presence of oral health indicators such as dental pain were [60]. According to these findings, we may conclude that we covered the most important aspects of oral health status in relation to OHRQoL.

Fifth, we chose not to measure personality traits (including coping) other than attitudinal variables in our quantitative studies, even though these traits are expected to contribute to differences in OHRQoL scores [61, 62](Chapter 5) and in oral health care behavior [5, 63, 64] (Chapter 6). Our first aim was to establish the associations between oral health, general health and OHRQoL (Chapter 5) and between oral health, general health and oral health care behavior (Chapter 6). We did not aim to find models with maximum explanatory power, in which case we would have had to include both personality traits and environmental factors. More generally, in order to reduce respondent burden and maintain sufficient power in the regression analyses without having to include large numbers of participants, we did not include all potentially relevant variables but made a selection of the most relevant ones as based on the literature and outcomes of our qualitative studies and in relation to our research aim.

Care-dependency, frailty, and oral vulnerability

Using Gobbens' definition of frailty as "a state of reduced psychological or physical reserve in combination with an increased risk for adverse outcomes" [65], our selection of frail people in RACFs was based on an indication of health care need (up to care level package 6) and hence pointed to the selection of mildly to severely frail people [66], with mild- to severe, but no complete, care-dependency [67]. People with complete care-dependency generally reside in nursing homes, where oral health care arrangements, by government policy, are (or should be) arranged in accordance with the Verenso (OGOLI) guideline [68, 69]. For the purpose of targeting frail people who were expected to face most barriers to oral health care, we targeted both frail and care-dependent community-dwelling older people (Chapters 2 and 3) and care-dependent elderly in RACFs (Chapters 2 to 6). For both groups, no protocolized oral health care delivery exists.

We hypothesized that frailty/care-dependency is a risk factor for impaired OHRQoL and unfavorable oral health care behavior. Consequently, we expected that the use of a care-dependency scale could give an indication of perceived oral health impacts and of oral health care needs and oral health care behavior [70]. However, our studies showed that the relations between the level of frailty/care-dependency, on the one hand, and oral health status, OHRQoL and dental service use, on the other, were not straightforward and significant associations were not found except for the association between reduced brushing frequency since the onset of care-dependency and a high level of care-dependency (Chapters 5 and 6). This could be explained in part by the fact that the medical, psychological and social impacts of frailty and care-dependency are highly individual, mediated by personal traits such as coping, and subject to change, especially as people grow older and start having more health problems [71, 72].

Indeed, frailty and care-dependency are broad concepts that have been shown to be of only limited use in predicting general health outcomes [73]. We therefore additionally explored the associations between oral health variables and oral health care behavior variables and separate frailty components, and found that some components of frailty and care-dependency have a direct relation to OHRQoL or dental service use while others do not (Chapters 5 and 6).

In light of our findings and the above considerations, rather than using 'frailty' or 'care dependency' as categorizations that can assist in establishing oral health care needs and planning, it may be more beneficial to use 'dental vulnerability' [74], or perhaps even better: 'oral vulnerability'. Oral vulnerability in this sense could be defined as a state of increased risk for adverse oral health outcomes due to a mix of unfavorable personal and environmental factors related to mental and physical health, social support situation, socio-economic status, personal traits, dependence, living environment, oral health status, and access to dental services. This thesis could be viewed as a step

towards identifying factors and behavioral pathways that are related to the oral vulnerability of frail older people in The Netherlands.

Current developments and initiatives in the field of (oral) health care in The Netherlands

Changes in institutionalization policy

As a result of current developments in Dutch health care planning, since 2015, people with 'light care-dependency' (care-level package 1-4) are no longer admitted to RACFs financed by national insurance schemes. This means that people with a similar care-level package as that of about 85% of our respondents that resided in RACFs will be home-dwelling in future years. This raises the question of how our results apply to this 'new' group of home-dwelling care-dependent people. In accordance with results from Hoeksema's studies [26], which included that the oral health of the large majority of both home-dwelling *and* institutionalized frail and care-dependent older Dutch people is poor, it can be expected that the oral health status and needs of this 'new' group will be largely comparable to those of our studied group.

However, the effects of institutionalization on oral health care behavior could cause notable differences in oral health between home-dwelling care-dependent people and the RACF residents of our studies. As indicated in Chapter 2, these effects comprise disorientation after becoming institutionalized and a changed and often unfavorable social support situation, both of which have proved to be associated with unfavorable oral health care behavior (Chapters 3, 6, and [75, 76]) and (oral health-related) quality of life (Chapter 5 and [77-79]).

Another major influence is the support and professional oral health care that these home-dwelling care-dependent people will receive. So far, consumption by and provision of oral health care to this group leaves much to be desired as reflected by generally poor oral health outcomes [16, 26, 70, 80, 81]. More generally, to date, there is no conclusive evidence to compare the effects of (residential) care-

home and own home environments on health outcomes and quality of life of older people [82].

Recent national oral health care initiatives

Partly on the basis of our results (Chapters 2 and 3) [30, 83], in 2016, a committee of national stakeholders that included the Dutch associations for patients, dentists, oral hygienists, denturists and health-care insurers and that was commissioned by the Dutch government determined four principal oral health care strategies [16, 80]. These strategies involve: 1) Developing lifecourse-proof oral health care (actions: 1a. inventorizing barriers to good oral health care; 1b. developing suitable measures to remove or mitigate these barriers; and 1c. involving direct stakeholders in these actions); 2) Implementing the 'Praktijkwijzer Mondzorg' (a practice guideline and checklists to assist professional oral health care providers in dental practices in providing adequate care to older people); 3) Making an inventory of existing oral care courses in order to improve these and enable integration into relevant general health care courses; 4) Assessing the options for integrating standardized oral health care routines into general health care protocols for home carers.

To contribute to the implementation of strategy 1, we plan to share our recent study results (Chapter 6) with the committee. The practice guideline of strategy 2 is mostly based on expert advice, since scientific evidence is lacking for most actions [84]. This thesis supplies new and additional evidence for a number of actions proposed in the guideline, such as monitoring the physical, mental and social support situations, and, especially, motivation-related factors, as well as a (more) frequent examination of the oral status.

The above developments will be supplemented and enhanced by the additional national initiatives that were announced in December 2016 by the Dutch Minister of Health, Welfare and Sport, which comprise a campaign to increase oral health awareness and a communication plan [85]. These initiatives may expand the possibilities for conveying oral health knowledge and messages to the patient and hence for creating a more positive oral health attitude and greater awareness of the

severity of and susceptibility [86] to oral impairments. This, in turn, will reduce motivational barriers to favorable oral health care behavior.

Overall conclusions and recommendations

Conclusions

In the qualitative studies, level and type of frailty were shown to influence people's perception of oral health and oral health care behaviors. Having natural teeth generally contributed to the quality of life of frail older people through a sense of achievement, pride, a sense of control, intactness, better oral function, more comfort, and a nicer appearance.

Frail elders associated continuation of established oral care behavior routines with self-worth, but gave up favorable oral health care behavior, in particular dental service use, once they became burdened with specific frailty-related impairments or discomforts. Such impairments influenced oral care behavior in different ways: chronic pain, low energy and low morale mainly affected oral care behavior through devaluation of oral health importance and reduced motivation. Physical constraints reduced self-efficacy beliefs with regard to oral hygiene practices, while bad past experiences, often in combination with reduced motivation, affected outcome expectations with regard to dental visits. Impaired mobility and dexterity, disorientation, failing memory, and lack of social support constituted structural barriers to oral care behavior.

In the course of increasing frailty, there seems to be a turning point where people lose their motivation for favorable oral health care behavior and for preserving natural teeth.

In the quantitative studies almost all of the above associations between oral health care behavior and frailty-related factors were confirmed, although only a few of them proved to be significant. Higher frequency of dental service use was mainly related to being dentate, whereas lower DSU since the onset of care-dependency was mainly associated with frailty-related

factors and need factors, especially with 'difficulty going to the dentist' and presence of a clinically assessed oral treatment need. Lower brushing frequency and reduced brushing frequency since the onset of care-dependency were mainly associated with frailty-related factors, of which 'not being capable of summoning the effort to brush' and a high care-dependency level were the most important.

People with lower DSU and lower brushing frequency had generally worse oral health and related quality of life, but only in the case of *reduced* DSU and brushing frequency since the onset of care-dependency were these associations significant. Although mostly not significantly related to level of care-dependency, oral health care behavior, especially brushing frequency and changed DSU since the onset of care-dependency, was related to specific frailty-related factors in a care-dependent older population.

The GOHAI-NL was shown to have satisfactory reliability and construct validity and can be used to measure OHRQoL in Dutch care-dependent and care-independent older people. Nevertheless, the GOHAI outcomes were associated with different variables in care-independent and care-dependent older subjects. Hence, OHRQoL outcomes should not be compared across care-dependent and care-independent populations without careful interpretation of these outcomes against specific factors that distinguish such populations, such as health factors and living environment.

Recommendations

1. Mind the knowledge gap

Future research should distinguish between home-dwelling and institutionalized frail and care-dependent elders, and be aimed at:

- Designing and testing interventions to increase motivation for favorable oral health care behavior;

- Assessing the cause-effect relations between favorable oral health care behavior and better clinical and perceived oral health outcomes in longitudinal studies using quantitative and qualitative research methods;
- Including personality traits, in particular coping profiles and self-worth, in the assessment of links between clinical and perceived oral health, frailty-related factors, OHRQoL and oral health care behavior;
- Identifying factors that constitute 'oral vulnerability' and ways to mitigate their negative (oral) health effects.

2. Monitor behavior and provide personalized oral health care

Dental professionals should start monitoring the ability and motivation of patients to seek professional oral care and to maintain oral hygiene already in a pre-frail stage. This involves asking for information about physical, mental and social factors and living circumstances that may influence oral health care behavior and regularly checking whether their (pre-)frail patients make dental visits. The same information should be acquired by general practitioners and (home-)nurses, in order to target patients who do not make dental visits.

In order to keep frail older people 'on board', dental professionals should make more home visits and discuss the health risks of unfavorable oral health care behavior in a pre-frail stage. Through these actions, they will convey the notion that oral health and oral health care are important in old age. After people become frail and care dependent, the role of caregivers in the preservation of favorable oral health care behavior increases and the focus is likely to shift to more basic oral health care. The dental professional could play a role in organizing oral health care around frail people and, where needed, make check-up visits and provide treatment.

All involved caregivers (dental professionals, general practitioners, (home-) carers/nurses, nursing home specialists, and family caregivers) and the frail older person him/herself should be alert to 'turning points' in physical, mental and social health, and in motivation, and should share relevant information within their care network.

Policy makers should devise strategies that take the reason for dental non-attendance into account. Distinguishing between people with a high and a low oral health risk profile and between those with high and low motivation and tailoring strategies accordingly could be a fruitful start. Care for frail elders should be tailored towards their personal situation, and providing individualized support and developing individual (oral) care plans should be facilitated through adequate oral care-organization and -reimbursement schemes.

3. Embed

Oral care for frail elders should be embedded in:

- An individual health care plan that is integrated into a personalized (health) care strategy;
- A multidisciplinary geriatric care network where the geriatrician, (geriatric) dentist, general practitioner, home-nurse, other (informal) caregivers and patient share information;
- Education of dental and medical workers at all levels: curriculum of dental but also of medical students, dental hygienists, dental assistants, and nurses, and in additional courses and in-service training for relevant groups;
- Education of patient and informal caregivers: elderly and their family caregivers should receive relevant information with regard to oral health risks and maintenance and be kept involved;
- Quality indicators of health care practices: oral health care outcomes should become indicative of the quality of (general) care provision in RACFs;
- Health policy: in order to truly engage with policy makers, high quality economic analyses of oral health care costs in relation to health benefits must be provided;
- Multidisciplinary geriatric research: dental and medical researchers, nursing researchers, general practitioners, sociologists and psychologists should conduct multidisciplinary studies;

- Insurance policies and remuneration systems: remuneration systems should facilitate longer consultations in case of (pre-)frail elders and cover the full costs of home-visits and of drawing up oral health care plans.

4. Mind the gap: communicate!

Not unusually, a gap exists between the oral health care aims of dental professionals and those of the patient. Norms and values of elders deviate more from professional standards than do norms of younger adults [87]. Dentists are trained to realize an optimal oral condition, dentition and function, whereas the elder patient is more likely to look for optimal oral comfort and adequate function and looks. The only way to bridge this gap, and thereby reduce the discrepancy between clinically assessed and perceived treatment need, is by effective communication. With the insights into oral health care behavior, OHRQoL, oral health perceptions and related impacts of and associations with frailty, as presented in this thesis, dental professionals will be helped to ask the right questions to make the process of shared decision making more effective, provide better oral health care and improve (oral) health outcomes.

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Chapter 8

Summary

Summary

Chapter 1 provides an introduction to the studies in this thesis.
Studies worldwide and in The Netherlands have shown that the oral health of many frail and care dependent older people, both home-dwelling and institutionalized, is poor. Poor oral health often negatively affects quality of life and can also increase frailty through impeding physical, mental and social functioning. Conversely, frail older people are particularly vulnerable to oral disorders, owing to complex interactions between oral health, systemic diseases, the use of medication, failing upkeep of oral hygiene and limited use of dental services. Besides, frailty and care-dependency tend to alter the experience, perception, and attitudes with regard to general health. This is expected to change the value attached to oral health, which in turn may change self-perceived oral health needs and oral health care behavior.

The Dutch Ministry of Health, Welfare and Sport is currently promoting the search for innovative and cost-effective patient-centered approaches to oral health care for frail older people. However, more needs to be known about the oral health views, attitudes, oral health care behavior and oral health care needs of frail older people, and how these issues relate to frailty-related factors, oral health factors and quality of life. Besides, the barriers with regard to the upkeep of oral hygiene and to dental service use, need to be identified for this group. The required information will help direct resources more effectively by identifying people who are likely to benefit from oral health care strategies and measures in terms of quality of life improvement.

The studies presented in this thesis yield information on views, attitudes, and needs of frail and care dependent older people with regard to oral health care, related oral health care behavior, and oral health-related quality of life.

The first study (Chapter 2) addressed the objective of assessing the impact of having natural teeth on the quality of life and the role of frailty in this relationship. A qualitative approach through in-depth open-ended interviews

was considered most appropriate. Interviews with 38 Dutch dentulous elders of varying frailty in residential aged care facilities (RACFs) or daycare centers in East-Netherlands were tape-recorded, transcribed, coded for content and analyzed. Additional information was collected on age, gender, living situation, use of dental prostheses, self-reported oral health, chronic disorders, and an index of frailty (Care Level Package, in Dutch: Zorgzwaartepakket ZZP; based on the type and intensity of received health care). Maximum variation in age, gender and type and level of care received by participants (ZZP-score 1-6) was sought.

Seven themes were identified in the relationship between having natural teeth and quality of life: pride and achievement; intactness; sense of control; oral function; appearance; comfort; and coping with and adaptation to disabilities. Having natural teeth generally had a positive effect on quality of life. Pride and achievement, intactness, and sense of control were most apparent for the most severely frail (ZZP 4-6). These people compared themselves with peers who were more often edentate, and valued the state of their teeth against the background of their declining health. The effect of coping with and adaptation to tooth loss was also most apparent for the most severely frail. Men generally cared less about having natural teeth than women regardless of their level of frailty.

It was concluded that quality of life of frail older people is positively influenced by having natural teeth, an effect that seems to increase with increasing frailty. The preservation of natural teeth contributes to a positive body image and self-worth. Oral care for frail people should aim to preserve natural teeth if feasible.

The second study (Chapter 3) aimed to explore the link between frailty and oral health care behavior, and to identify barriers and motivating factors with regard to oral self-care and professional oral health care. To this end, open-ended interviews were conducted with 51 elderly persons of varying frailty in residential aged care facilities (RACFs) and daycare centers.

From our analyses, three major themes and five sub-themes emerged. The major themes indicated that frail elders: A) favor long-established oral hygiene routines to sustain a sense of self-worth; B) discontinue oral health care behavior -they first give up dental visits, then oral hygiene routines-, when burdened by severe general health complaints, in particular chronic pain, low morale, and low energy, because they: B1) lack belief in the results of dental visits and tooth cleaning; B2) trivialize oral health and oral health care; and B3) consciously use their sparse energy for priorities other than oral health care; and finally C) experience psychological and social barriers to oral health care when institutionalized because of: C1) disorientation and C2) inconveniencing social supports.

It was concluded that level and type of frailty influence people's perspectives of oral health and related behaviors. Frail elders associate oral hygiene with self-worth, but readily abandon visits to a dentist unless they feel that the dentist can relieve specific problems. The discontinuation of oral care by frail elderly can be interpreted as a manifestation of adaptive development in the context of their adjusting goals and behavioral strategies.

The third study (Chapter 4) addressed the objective of translating the English version of the Geriatric Oral Health Assessment Index (GOHAI) into a Dutch version (GOHAI-NL) and of validating this version. The GOHAI consists of 12 questions (items) in 3 dimensions (physical functioning, psychosocial functioning, and pain and discomfort) and is one of the most frequently used instruments for measuring oral health-related quality of life of adults, especially designed for older people.

After its translation into Dutch, the resulting version was discussed by an expert panel, back-translated to the original, pilot-tested and assessed for cognitive and conceptual equivalence.

The translated GOHAI was tested in two groups of cognitively alert people aged 65 and over: a care-independent group (n = 109, mean age 73.1 ± 5,4 years) and a care-dependent group (n = 118, mean age 85.6 ± 7.0 years). Internal

consistency of the questionnaire was confirmed by Cronbach's alphas of 0.86 in the care-independent, and 0.80 in the care-dependent group. In general, item-total score correlations were between 0.4 and 0.7 for both groups. Item-dimension and dimension-total correlations were between 0.30 and 0.78 and around 0.7 respectively for the dimensions 'physical functioning' and 'psychosocial functioning', but lower (between 0.13 and 0.44 and around 0.45 respectively) for the dimension 'pain and discomfort'. The test-retest correlation of the total GOHAI score was 0.88 (intraclass correlation coefficient ICCs per item: 0.62 – 0.88) in the care-independent group and 0.93 (ICCs per item: 0.64 – 0.91) in the care-dependent group.
Statistically significant correlations in the expected direction were found between GOHAI scores and most oral health-related variables.
It was concluded that the GOHAI-NL has satisfactory reliability and validity and can be used to measure OHRQoL in Dutch care-dependent and care-independent older people.

The fourth study (Chapter 5) addressed the objective of exploring the health-related associates of oral health-related quality of life in a care-dependent and a care-independent population. The relationships between oral health factors and general health factors (including physical, mental, and social health domains), and oral health-related quality of life were examined in care-independent participants (n = 109) recruited from the Nijmegen dental school, and care-dependent participants (n = 126) from residential aged care facilities (RACFs).

Data collected included: Geriatric Oral Health Assessment Index (GOHAI) scores, age, gender, socioeconomic status, number of teeth and occluding pairs, presence of carious teeth, presence of removable dental prostheses, clinically assessed treatment need, and self-reported general health, and, only for care-dependent participants: care-dependency level (ZZP) and health domain variables: physical, mental (SF-12: Physical and Mental Component Summary scores), and social support (ENRICHD social support index). Multiple

linear regression analyses were performed to assess the associations with GOHAI scores.

For care-independent participants, regression models revealed significant associations ($p \leq 0.05$) between higher GOHAI scores and higher age and absence of a clinically assessed treatment need; absence of removable dental prostheses was near-significant ($p=0.053$). For care-dependent participants, only the association with absence of a clinically assessed treatment need was significant. Self-reported general health and care-dependency level were not significantly associated with GOHAI. However, when these variables were substituted by the health domain variables, only (higher level of) social support was significantly associated with higher GOHAI scores.

It was concluded that GOHAI outcomes are associated with different variables in care-independent and care-dependent older subjects. In care-dependent subjects, GOHAI outcomes are more strongly related to social support than to oral health factors or other general health factors. These findings suggest that GOHAI outcomes should not be compared across care-dependent and care-independent populations without careful interpretation of the contextual factors that characterize these groups.

The fifth study (Chapter 6) aimed to assess the associations between oral care behavior and frailty-related factors in a care-dependent population. It is unclear which factors are associated with unfavorable oral health care behavior which is often found in care-dependent people and to what extent these factors are frailty-related. We therefore explored: 1) which frailty- and non-frailty related predisposing, enabling and need factors are associated with a) dental service use (DSU) frequency, b) changed DSU after the onset of care-dependency, c) brushing frequency, and d) changed brushing frequency after the onset of care-dependency; and 2) if unfavorable oral health care behavior is related to unfavorable oral health outcomes in older people with different levels of care-dependency (ZZP).

126 participants aged 65 and over in residential aged care facilities (RACFs) underwent a clinical oral examination and answered questionnaires covering oral and general health factors (oral health-related quality of life, psychological, social and oral health behavioral issues), gender, age, and socioeconomic status. We analyzed the associations between dependent variables (DSU frequency, changed DSU, brushing frequency, changed brushing frequency) and predicting factors and oral health outcomes, using bivariate analyses and logistic binary regression.

Lower DSU frequency was mainly related to non-frailty-related predisposing factors, especially being edentate (OR=3.75; CI: 1.20-11.71; p=0.023) and having lower socioeconomic status (OR=1.74; CI: 0.97-3.14; p=0.065); Changed (reduced) DSU frequency after the onset of care-dependency was mainly associated with enabling and need factors, especially 'difficulty going to the dentist' (OR=4.98; CI: 1.85-13.36; p=0.001) and clinically assessed treatment need (OR=3.23; CI:1.24-8.42; p=0.016); lower brushing and changed (reduced) brushing frequency to frailty-related enabling factors, and, in case of reduced frequency were significantly related to 'not being capable of summoning the effort to brush' (OR=8.28; CI: 1.44-47.56; p=0.018) and high care-dependency level (OR=4.14; CI: 1.05-16.36; p=0.043). People with lower and especially those with *reduced* DSU and brushing frequencies after the onset of care-dependency, had generally worse oral health outcomes and related quality of life than people with higher DSU and brushing frequencies.

It was concluded that oral health care behavior, especially brushing frequency and reduced dental service use after the onset of care-dependency, is related to specific frailty-related factors in a care-dependent older population. Hence, dentists and other (oral) care-providers should be alert to these factors.

The general discussion (Chapter 7) integrates key results and issues in the context of the academic discourse and the current Dutch developments in oral health care for frail and care-dependent elders. These comprise:

- *Turning points and motivation:* Oral health care behavior of frail and care-dependent elders is to a large extent explained by motivation. With increasing frailty, there seems to be a turning point where people give up their usual oral health care behavior and caring about preservation of natural teeth.
- *Oral health outcomes, care pathways, and access to oral health care:* Our study results add to the evidence of poor oral health and low dental service use of frail Dutch elders. Oral health care (behavioral) pathways found in our qualitative studies were compared to the outcomes of our quantitative studies. The majority of associations were confirmed while not all at significance level and although causal links could not be established due to the cross sectional study design.
- *GOHAI and measuring oral health-related quality of life*: Instruments like GOHAI-NL, although valid and reliable, should be supplemented by contextual information if one wishes to understand the meaning and significance of OHRQoL outcomes. This information can best be derived through qualitative methods.
- *Frailty versus oral vulnerability:* Since the use of frailty or care-dependency levels seems limited in predicting oral health care behavior or oral health-related quality of life, it is suggested that the level of 'oral vulnerability', indicating the risk for adverse oral health outcomes, be used as a categorization that can assist in determining oral health care needs and planning.
- *Study design:* The use of both qualitative and quantitative research methods added value. The information derived from our qualitative studies was important for formulating relevant questions that were used in the quantitative studies. Besides, the qualitative studies yielded detailed information and context for interpretation of the findings of our quantitative studies.
- *Current developments and initiatives in the field of (oral) health care in the Netherlands:* The study results presented in this thesis contribute to the

development of life-course proof oral care proposed by the Dutch Ministry of Health, Welfare and Sports; in particular through identifying barriers and motivating factors for favorable oral health care behavior.

Main conclusions

1. The level and type of frailty influence people's perspectives of oral health and related behaviors, and different frailty-related factors affect oral health care behavior in different ways.
2. There seems to be a turning point where frail and care-dependent people give up their established oral health care routines and do not mind losing teeth because perceived efforts outweigh perceived benefits of oral (self-) care.
3. Unfavorable oral health care behavior is related to lower socioeconomic and having complete removable dental prostheses, and, in people with higher levels of care-dependency, to motivational factors (like low energy, low importance attached to oral health, and inability to summon the effort to brush), and also to perceived difficulty going to the dentist.
4. The GOHAI-NL has satisfactory reliability and construct validity.
5. GOHAI outcomes were associated with different variables in care-independent and care-dependent older subjects. Hence, GOHAI-outcomes should not be compared across populations without careful interpretation of these outcomes against specific factors that distinguish such populations.

Main recommendations

1. *Mind the knowledge gap:* future research could assess the effects of motivation-related interventions, personality traits, and of factors that constitute 'oral vulnerability'.
2. *Monitor behavior and provide personalized oral health care:* both dental professionals and other involved care-providers should start monitoring factors that might affect oral health care-related behavior and share this

information, starting from a pre-frail stage. Oral health care strategies should be personalized, partly based on oral vulnerability, while health care strategies at population level should take the reasons for dental non-attendance into account.

3. *Embed:* oral care for frail elders should be embedded in: a multidisciplinary geriatric care-network, education of dental and medical workers at all levels, education of patient and family caregivers, quality indicators of (oral) health care practices, multidisciplinary geriatric research, insurance policies, and remuneration systems.
4. *Mind the communication gap:* effective communication between dental professional and patient will be aided by sensitizing dentists to issues that might be of importance to the patient with regard to oral health care behavior, as presented in this thesis.

Chapter 9

Samenvatting (Summary in Dutch)

Samenvatting

Hoofdstuk 1: inleiding

Onderzoek wereldwijd en in Nederland laat zien dat de mondgezondheid van veel kwetsbare en zorgafhankelijke ouderen, zowel thuiswonend als in verzorgings- of verpleeghuizen, veel te wensen overlaat. Een zwakke mondgezondheid heeft over het algemeen een negatieve invloed op de levenskwaliteit en kan de mate van kwetsbaarheid verhogen door lichamelijk, geestelijk en sociaal functioneren te belemmeren. Tegelijkertijd zijn juist de kwetsbare ouderen vatbaarder voor orale aandoeningen als gevolg van complexe interacties tussen de mondgezondheid, systeemziekten, (poly)medicatie, gebrekkige mondhygiëne of doordat ze minder gebruikmaken van professionele tandheelkundige zorgverlening. Kwetsbaarheid en zorgafhankelijkheid zijn daarnaast van invloed op de beleving van en houding jegens de algemene gezondheid. Verwacht wordt dat kwetsbaarheid en zorgafhankelijkheid ook de waardering van het belang van mondgezondheid beïnvloeden, hetgeen zijn weerslag heeft op het mondzorggedrag en de behoefte aan professionele mondzorg.

Het Nederlandse Ministerie van Volksgezondheid, Welzijn en Sport investeert momenteel in innovatieve en kosteneffectieve persoonsgerichte benaderingen om de mondgezondheid van kwetsbare ouderen te verbeteren. Daartoe moet echter eerst onderzocht worden welke visie, behoeften, houding en gedrag ten aanzien van mondzorg en mondgezondheid kwetsbare ouderen hebben en hoe deze aan kwetsbaarheid, mondgezondheid en kwaliteit van leven gerelateerd zijn. Ook is er weinig bekend over de barrières voor mondverzorging en tandartsbezoek. Informatie hierover is nodig om beschikbare middelen effectiever in te kunnen zetten. Deze informatie kan ook helpen om (groepen) ouderen te identificeren die het meest baat hebben - in termen van verbetering van de levenskwaliteit - bij bepaalde strategieën om de mondgezondheid van kwetsbare ouderen te verbeteren.

De studies in dit proefschrift geven inzicht in de visie, behoeften, houding en gedrag van kwetsbare en zorgafhankelijke ouderen ten aanzien van mondzorg, mondgezondheid en mondgezondheid–gerelateerde kwaliteit van leven.

In de eerste studie (hoofdstuk 2) is onderzocht welke invloed het hebben van eigen tanden en kiezen op de kwaliteit van leven van kwetsbare ouderen heeft en welke rol kwetsbaarheid hierbij speelt. Daartoe is kwalitatief onderzoek uitgevoerd middels open (diepte) interviews met 38 Nederlandse dentate ouderen in verzorgingshuizen of bij dagopvang-lokaties in Oost-Nederland. De interviews werden opgenomen, uitgeschreven , fragmenten naar thema gecodeerd, en geanalyseerd met behulp van kwalitatieve (thematische) analyse. Daarnaast werden aanvullende gegevens verzameld over leeftijd, geslacht, woonsituatie, aanwezigheid van uitneembare gebitsprothesen, zelf-gerapporteerde mondgezondheid, chronische ziekten, en zorgzwaarte (ZorgZwaartePakket (ZZP)-index, hetgeen het type en de intensiteit van de ontvangen zorg weergeeft). Gestreefd werd naar maximale variatie in leeftijd, geslacht en mate van kwetsbaarheid van deelnemers (ZZP score 1-6).

Zeven thema's werden geïdentificeerd met betrekking tot de relatie tussen het hebben van eigen tanden en kiezen en de kwaliteit van leven: trots en prestatie; intactheid; gevoel van controle; gebitsfuncties; uiterlijk; comfort; en het omgaan met en aanpassen aan beperkingen. Het hebben van eigen tanden en kiezen had in het algemeen een positief effect op de levenskwaliteit. De thema’s trots en prestatie, intactheid en gevoel van controle waren het meest duidelijk voor de meest kwetsbaren (ZZP 4-6). Deze mensen vergeleken zichzelf met leeftijdgenoten die veelal edentaat waren en waardeerden hun gebitsstatus vanuit het perspectief van hun afnemende gezondheid. Het effect van het kunnen omgaan met en aanpassen aan het verlies van tanden en kiezen was eveneens het duidelijkst voor de meest kwetsbaren. Het maakte mannen in het algemeen minder uit of ze eigen tanden en kiezen hadden dan vrouwen, ongeacht de mate van kwetsbaarheid.

De conclusie was dat de kwaliteit van leven van kwetsbare ouderen in het algemeen positief beïnvloed wordt door het hebben van eigen tanden en kiezen. Deze invloed lijkt groter bij een hogere mate van kwetsbaarheid. Het behoud van eigen tanden en kiezen draagt bij aan een positief zelfbeeld en eigenwaarde. Mondzorg voor kwetsbare ouderen zou derhalve gericht moeten zijn op het behoud van het eigen gebit indien mogelijk.

Doel van de tweede studie (hoofdstuk 3) was om de link tussen kwetsbaarheid en mondzorggedrag te onderzoeken, en om barrières en motiverende factoren te identificeren met betrekking tot de eigen mondverzorging en professionele mondzorg. Hiertoe werden open (diepte) interviews gehouden met 51 ouderen met verschillende gradaties van kwetsbaarheid in verzorgingshuizen of bij dagopvang-lokaties in Oost Nederland. Daarnaast werden gegevens over leeftijd, geslacht, woonsituatie, aanwezigheid van uitneembare gebitsprotheses, zelf-gerapporteerde mondgezondheid, chronische ziekten, en zorgzwaarte (ZZP-index) verzameld.

Uit kwalitatieve analyses kwamen drie hoofd- en vijf subthema's naar voren. De hoofdthema's gaven aan dat kwetsbare ouderen: A) zolang mogelijk vasthouden aan vertrouwde mondverzorgingsroutines om een gevoel van eigenwaarde te houden; B) bij ernstige gezondheidsklachten (met name chronische pijn, gebrek aan levenslust en energie) eerst het tandartsbezoek opgeven en uiteindelijk ook de mondverzorgingsroutines omdat ze (B1) gebrek aan vertrouwen hebben in het resultaat van eigen mondverzorging en van tandartsbezoek, (B2) hun mondgezondheid en de mondzorg bagatelliseren en omdat ze (B3) bewust hun beperkte energie gebruiken voor andere prioriteiten dan mondzorg; en C) psychische, met name (C1) desoriëntatie, en (C2) sociale belemmeringen voor mondzorg en tandartsbezoek ervaren (de juiste hulp is er niet of men wil er niet om vragen) wanneer ze in verzorgingshuizen terechtkomen.

De conclusie was dat het type en de mate van kwetsbaarheid de visie, verwachtingen, behoeften, houding en gedrag ten aanzien van mondzorg en

mondgezondheid beïnvloeden. Kwetsbare ouderen associëren mondverzorging met eigenwaarde, maar geven tandartsbezoek gemakkelijk op naarmate ze kwetsbaarder worden, tenzij ze geloven dat de tandarts specifieke problemen kan verhelpen. Wanneer kwetsbare ouderen niet langer hun tandarts bezoeken of hun mond verzorgen, kan dit worden geïnterpreteerd als een adaptieve ontwikkeling in de context van het aanpassen van doelen en gedragsstrategieën.

De derde studie (hoofdstuk 4) had als doel om de Engelse versie van de Geriatrische Oral Health Assessment Index (GOHAI) in een Nederlandse versie (GOHAI-NL) te vertalen en deze te valideren. De GOHAI bestaat uit 12 vragen (items) in 3 dimensies (fysiek functioneren, psychosociaal functioneren, pijn en ongemak) en is een van de meest gebruikte instrumenten voor het meten van mondgezondheid-gerelateerde kwaliteit van leven van volwassenen. De GOHAI is oorspronkelijk ontworpen voor ouderen (65 jaar en ouder). Na vertaling in het Nederlands werd deze versie besproken door een panel van deskundigen, terugvertaald naar de originele versie, middels een pilot getest en beoordeeld op cognitieve en conceptuele gelijkwaardigheid.

De vertaalde GOHAI werd getest in twee groepen cognitief gezonde mensen van 65 jaar en ouder: een zorg-onafhankelijke groep (n = 109, gemiddelde leeftijd 73,1 ± 5,4 jaar) en een zorgafhankelijke groep (n = 118, gemiddelde leeftijd 85,6 ± 7,0 jaar). De interne consistentie van de vragenlijst werd bevestigd door Cronbach's alfa's van 0,86 in de zorg-onafhankelijke en 0,80 in de zorg-afhankelijke groep. In het algemeen waren item-totaalscore correlaties tussen de 0,4 en 0,7 in beide groepen. Item-dimensiescore- en dimensie-totaalscore-correlaties waren respectievelijk tussen 0,30 en 0,78 en rond 0,7 voor de dimensies 'fysiek functioneren' en 'psychosociaal functioneren', maar lager voor de dimensie 'pijn en ongemak': respectievelijk tussen 0,13 en 0,44 en rond de 0,45. De test-hertest correlatie van de totale GOHAI score was 0,88 (intraclass correlation coefficients ICCs per item: 0,62-0,88) in de zorg-onafhankelijke groep en 0,93 (ICCs per item: 0,64-0,91) in de zorg-afhankelijke

groep. GOHAI scores waren statistisch significant gecorreleerd in de verwachte richting met de meeste mondgezondheid-gerelateerde variabelen. Geconcludeerd werd dat de betrouwbaarheid en validiteit van de GOHAI-NL voldoende is om de mondgezondheid-gerelateerde kwaliteit van leven te meten van Nederlandse zorgafhankelijke en zorg-onafhankelijke ouderen.

In de vierde studie (hoofdstuk 5) werd onderzocht welke gezondheid-gerelateerde factoren geassocieerd zijn met mondgezondheid-gerelateerde kwaliteit van leven (uitgedrukt in GOHAI scores) in een zorgafhankelijke en een zorg-onafhankelijke groep ouderen. De relaties tussen mondgezondheid-gerelateerde factoren, gezondheid-gerelateerde factoren (met inbegrip van fysieke, mentale en sociale gezondheid-domeinen) en mondgezondheid-gerelateerde kwaliteit van leven werden onderzocht onder zorg-onafhankelijke deelnemers uit de tandheelkunde praktijk van het Radboudumc Nijmegen (n = 109) en onder zorgafhankelijke deelnemers uit verzorgingshuizen (n = 126). Verzamelde gegevens betroffen: GOHAI scores, leeftijd, geslacht, sociaaleconomische status, het aantal gebitselementen en occlusale eenheden, aanwezigheid van carieuze gebitselementen, aanwezigheid van uitneembare gebitsprothesen, klinisch vastgestelde en ervaren behandelnoodzaak en zelfgerapporteerde algemene gezondheid. Alleen voor zorgafhankelijke deelnemers werden ook de zorgzwaarte (ZZP-index) en variabelen met betrekking tot specifieke gezondheidsdomeinen geïncludeerd: fysiek, mentaal (SF-12: fysieke en mentale 'component summary scores'), en sociaal (ENRICHD sociale ondersteuning index). Meervoudige lineaire regressie analyses werden uitgevoerd om de associaties met GOHAI scores te berekenen.

Voor zorg-onafhankelijke deelnemers lieten regressie modellen significante associaties ($p \leq 0,05$) zien tussen hogere GOHAI scores en hogere leeftijd en afwezigheid van een klinisch vastgestelde behandelnoodzaak; afwezigheid van uitneembare gebitsprothesen was bijna significant ($p=0,053$). Voor zorgafhankelijke deelnemers was er alleen een significante associatie

tussen hogere GOHAI scores en afwezigheid van een klinisch vastgestelde behandelnoodzaak. De zelfgerapporteerde algemene gezondheid en de mate van zorgafhankelijkheid waren niet significant geassocieerd met GOHAI scores. Wanneer deze variabelen werden vervangen door de variabelen van afzonderlijke gezondheidsdomeinen, was alleen een hogere mate van sociale ondersteuning significant geassocieerd met hogere GOHAI scores.

Geconcludeerd werd dat GOHAI scores zijn geassocieerd met verschillende variabelen in zorg-onafhankelijke en zorgafhankelijke ouderen. In zorgafhankelijke ouderen zijn GOHAI uitkomsten sterker gerelateerd aan sociale ondersteuning dan aan mondgezondheid-gerelateerde factoren of aan algemene gezondheid-gerelateerde factoren. Deze bevindingen impliceren dat GOHAI uitkomsten niet mogen worden vergeleken tussen zorgafhankelijke en zorg-onafhankelijke populaties zonder zorgvuldig de verschillende contexten te interpreteren waarin deze uitkomsten verkregen zijn.

Het doel van de vijfde studie (hoofdstuk 6) was om in een populatie van zorgafhankelijke ouderen associaties tussen mondzorggedrag en kwetsbaarheidfactoren te onderzoeken. Hiermee wordt inzicht verkregen in welke factoren samenhangen met ongunstig mondzorggedrag en in welke mate deze factoren gerelateerd zijn aan kwetsbaarheid. Daartoe werd bij mensen met verschillende niveaus van zorgzwaarte (ZZP-index) onderzocht: 1) welke kwetsbaarheid- en niet-kwetsbaarheid-gerelateerde predisponerende, faciliterende en behoeftegerelateerde factoren geassocieerd zijn met a) gebruiksfrequentie van tandheelkundige diensten (GTD) ; b) veranderde gebruiksfrequentie van tandheelkundige diensten sinds zorgafhankelijkheid (GTD-Z); c) poetsfrequentie (PF); en d) veranderde poetsfrequentie sinds zorgafhankelijkheid (PF-Z); en 2) of ongunstig mondzorggedrag gerelateerd is aan ongunstige mondgezondheidsuitkomsten.

126 deelnemers van 65 jaar in verzorgingshuizen ondergingen een klinisch mondonderzoek en beantwoordden vragen over algemene gezondheid en mondgezondheid (inclusief mondgezondheid-gerelateerde kwaliteit van

leven, psychologische, sociale en mondgezondheid-gerelateerde gedragsfactoren), geslacht, leeftijd en sociaaleconomische status. De associaties tussen de afhankelijke variabelen (GTD, GTD-Z, PF, PF-Z) en de voorspellende factoren en mondgezondheidsuitkomsten werden geanalyseerd met behulp van bivariate analyses en binaire logistische regressie.

Een lagere GTD was vooral geassocieerd met niet-kwetsbaarheid-gerelateerde predisponerende factoren, in het bijzonder edentaat zijn (OR = 3,75; CI: 1,20-11,71; p = 0,023) en een lagere sociaaleconomische status (OR = 1,74, CI: 0,97-3,14; p = 0,065); een afgenomen GTD-Z werd vooral geassocieerd met faciliterende factoren en behoefte-gerelateerde factoren, in het bijzonder 'moeite met naar de tandarts gaan' (OR = 4,98; CI: 1,85-13,36; p = 0,001) en met een klinisch vastgestelde behandelnoodzaak (OR = 3,23; CI: 1,24-8,42; p = 0,016). Een lagere PF en een afgenomen PF-Z waren vooral geassocieerd met kwetsbaarheid-gerelateerde faciliterende factoren en in het geval van PF-Z significant geassocieerd met ‘de moeite niet op kunnen brengen om te poetsen’ (OR = 8,28; CI: 1,44-47,56; p = 0,018) en met een hoge zorgzwaarte (OR = 4,14; CI: 1,05-16,36; p = 0,043). Mensen die minder gebruikmaakten van tandheelkundige diensten en in het bijzonder degenen die hier minder gebruik van maakten en minder vaak poetsten sinds ze zorgafhankelijk waren geworden, hadden over het algemeen slechtere mondgezondheidsuitkomsten en een lagere mondgezondheid-gerelateerde kwaliteit van leven dan mensen met een hogere GTD en hogere poetsfrequenties.

Geconcludeerd werd dat mondzorggedrag, met name verminderd gebruik van tandheelkundige diensten en verlaagde poetsfrequentie sinds de zorg-afhankelijkheid, gerelateerd is aan een aantal specifieke kwetsbaarheid-gerelateerde factoren. Tandartsen en andere (mond) zorgverleners moeten derhalve alert zijn op deze factoren.

In de algemene discussie (hoofdstuk 7) worden de belangrijkste bevindingen uit de in dit proefschrift beschreven onderzoeken geïntegreerd en in de context

geplaatst van het academisch discours en de huidige ontwikkelingen in de mondzorg voor kwetsbare en zorgafhankelijke ouderen in Nederland. Hoofdpunten zijn:

- *Kantelpunten en motivatie*: mondzorggedrag van kwetsbare en zorgafhankelijke ouderen is voor een groot deel te verklaren door motivatie. Met toenemende kwetsbaarheid lijkt er een kantelpunt te zijn waarbij mensen hun gebruikelijke mondzorggedrag opgeven en hun motivatie voor het behoud van natuurlijke tanden verliezen.
- *Mondgezondheid, zorgpaden en toegang tot mondzorg*: de resultaten van ons onderzoek dragen bij aan de wetenschappelijke bewijsvoering dat zorgafhankelijke ouderen in Nederland over het algemeen een slechte mondgezondheid hebben en beperkt gebruikmaken van tandheelkundige diensten. De patronen in het gedrag van de mondzorg die werden gevonden in de kwalitatieve studies (1 en 2) werden vergeleken met de uitkomsten van onze kwantitatieve studies (4 en 5). De meerderheid van de door kwalitatieve methoden gevonden verbanden werden bevestigd, hoewel ze niet allemaal statistisch significant waren en causale verbanden niet konden worden vastgesteld als gevolg van de cross-sectionele studie-opzet.
- *GOHAI en het meten van mondgezondheid-gerelateerde kwaliteit van leven:* informatie verkregen middels vragenlijsten zoals de GOHAI-NL, hoewel valide en betrouwbaar, zou moeten worden aangevuld met contextuele informatie om de betekenis en het belang van verkregen uitkomsten te kunnen begrijpen. Deze informatie kan het best worden verkregen door middel van kwalitatieve methoden.
- *Kwetsbaarheid versus orale kwetsbaarheid:* het gebruik van kwetsbaarheid- of zorgzwaarteniveaus heeft slechts beperkte waarde voor het voorspellen van mondzorggedrag of van de mondgezondheid-gerelateerde kwaliteit van leven. Daarom wordt gesuggereerd om in de toekomst het niveau van 'orale kwetsbaarheid', dat het risico op nadelige mondgezondheidseffecten aangeeft, te gebruiken als een

categorisering die kan helpen bij het bepalen van mondzorg-gerelateerde behoeften en planning.

- *Studie-ontwerp:* het gebruik van zowel kwalitatieve als kwantitatieve onderzoeksmethoden had toegevoegde waarde. Zo waren de kwalitatieve studies belangrijk voor het formuleren van relevante vragen voor de kwantitatieve studies. Daarnaast leverden de interviews met kwetsbare en zorgafhankelijke ouderen gedetailleerde contextuele informatie voor de interpretatie van de resultaten van de kwantitatieve studies.
- *Huidige ontwikkelingen en initiatieven op het gebied van (mond) gezondheidszorg in Nederland*: de in dit proefschrift gepresenteerde studieresultaten dragen bij aan de door het Ministerie van Volksgezondheid, Welzijn en Sport voorgestelde ontwikkeling van levensloopbestendige mondzorg, met name door identificatie van belemmerende en stimulerende factoren voor het op peil houden van mondzorg en mondverzorging.

Conclusies

1. De mate en het type kwetsbaarheid beïnvloeden het perspectief op mondgezondheid en mondzorggedrag. Verschillende kwetsbaarheid-gerelateerde factoren beïnvloeden mondzorggedrag op verschillende manieren.
2. Er lijkt een kantelpunt te zijn waarop kwetsbare en zorgafhankelijke ouderen hun mondverzorgingsroutines opgeven en het hen niet langer uitmaakt of ze tanden en kiezen verliezen, omdat de vermeende inspanningen niet langer opwegen tegen de vermeende voordelen van tandartsbezoek en mondverzorging.
3. Ongunstig mondzorggedrag is gerelateerd aan lagere sociaaleconomische status en het hebben van volledige gebitsprothesen en naarmate mensen in hogere mate zorgafhankelijk zijn ook aan motivatie-gerelateerde factoren

(zoals gebrek aan energie, lage prioritering van mondgezondheid, en het niet kunnen opbrengen van de inspanning om te poetsen) en aan ervaren moeilijkheden om naar de tandarts te gaan.

4. De GOHAI-NL is voldoende betrouwbaar en valide.
5. GOHAI uitkomsten zijn geassocieerd met verschillende variabelen onder zorg-onafhankelijke en zorgafhankelijke ouderen. Daarom kunnen GOHAI uitkomsten van verschillende populaties niet worden vergeleken zonder een zorgvuldige interpretatie van deze uitkomsten in het licht van specifieke factoren die dergelijke populaties onderscheiden.

Aanbevelingen

1. *Let op de kennisklоof*: aanbevolen wordt om onderzoek te doen naar de effecten van motivatie-gerelateerde interventies en van persoonlijkheidskenmerken op mondzorggedrag en mondgezondheid-gerelateerde kwaliteit van leven, en naar factoren die bepalend zijn voor 'orale kwetsbaarheid'.
2. *Monitor gedrag en bied persoonsgerichte mondzorg*: zowel tandheelkundige professionals en andere betrokken zorgverleners zouden al vanaf een pre-kwetsbare fase factoren moeten monitoren die de mondgezondheid en het mondzorggedrag van ouderen kunnen beïnvloeden en deze informatie moeten uitwisselen. Mondzorg-strategieën moeten op persoonsniveau worden ontwikkeld, mede op basis van orale kwetsbaarheid. Anderzijds is het realistisch om op populatieniveau bij de ontwikkeling van mondzorg-strategieën rekening te houden met de redenen voor verminderd gebruik van tandheelkundige diensten.
3. *Integreer:* mondzorg voor kwetsbare ouderen moet worden ingebed in: een multidisciplinair geriatrisch zorg-netwerk, de opleidingen van tandheelkundige en medische professionals op alle niveaus, voorlichting aan patiënten en mantelzorgers, kwaliteitsindicatoren van (mond-)

gezondheidszorg, multidisciplinair geriatrisch onderzoek, verzekerings-beleid en beloningssystemen.

4. *Let op de communicatie-kloof:* Effectieve communicatie tussen mondzorgverlener en patiënt wordt verbeterd als mondzorgverleners alert zijn op zaken die van belang kunnen zijn voor het mondzorggedrag van de patiënt, zoals beschreven in dit proefschrift.

Annex 1:

GOHAI-NL

Annex 1

GOHAI- NL

De volgende vragen gaan over de afgelopen drie maanden.

1. Hoe vaak hebt u de keuze van wat u eet, of de hoeveelheid die u eet, beperkt vanwege problemen met uw tanden of kunstgebit?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

2. Hoe vaak hebt u last gehad bij het bijten of kauwen van eten, zoals taai vlees of appels?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

3. Hoe vaak hebt u met gemak uw eten kunnen doorslikken?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

4. Hoe vaak hebt u uw tanden of kunstgebit als een probleem ervaren bij het spreken?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

5. Hoe vaak hebt u zonder ongemak kunnen eten wat u wilde?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

6. Hoe vaak hebt u uw contact met anderen beperkt door de conditie van uw tanden of kunstgebit?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

7. Hoe vaak was u tevreden of blij met hoe uw tanden, tandvlees of kunstgebit eruit zien?
   □ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

8. Hoe vaak hebt u medicijnen gebruikt tegen pijn of ongemak in het gebied van uw mond?

□ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

9. Hoe vaak hebt u zich zorgen gemaakt om problemen met uw tanden, tandvlees of kunstgebit?

□ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

10. Hoe vaak voelde u zich nerveus of in verlegenheid gebracht door problemen met uw tanden, tandvlees of kunstgebit?

□ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

11. Hoe vaak hebt u zich ongemakkelijk gevoeld bij het eten in gezelschap van anderen door problemen met uw tanden of kunstgebit?

□ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

12. Hoe vaak waren uw tanden of uw tandvlees gevoelig voor hitte, kou of snoep?

□ nooit □ zelden □ af en toe □ vaak □ zeer vaak of altijd

Annex 2:

Invited Commentary: Qualitative Research is Important For All Prosthodontists

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Editorial

On Patient-Mediated Qualitative Treatment Concerns

These are exciting yet anxiety-provoking times for prosthodontists. The past three decades animated and largely defined the speed of change in our traditional treatment protocols as we absorbed osseo-integration and CAD/CAM techniques into routine treatment planning. The interval also provided scope for other disciplines to rethink treatment directions—especially in periodontics—and for general dentists to expand their prosthodontic scope. The main beneficiaries of treatment techniques were of course partially and completely edentulous patients, although those with advanced periodontal disease were also grateful recipients of the new protocols. Nonetheless, interdisciplinary fault lines, together with a near-populist implant therapy approach backed by strong commercial initiatives, remind us that compelling patient-mediated concerns—often related to finances and age—tended to fall between the cracks and remain insufficiently prioritized.

Dentists continue to deal with lingering mixed feelings about quasi-herodontic treatment narratives as opposed to prudent and relatively inexpensive ones. Moreover, traditional oral rehabilitation concerns are readily challenged by a panacea mindset that mixes implantomania with exclusive quantitiative research conclusions influenced by professional pride and different degrees of faith in biotechnologic advances. A squall of treatment-planning ambiguity has emerged to complicate patient management in the context of global and dramatic increases in life expectancy and shifts in societal pyramids. Reliance on impressive implant therapy outcomes should not automatically be applied to aging patients. A more serious commitment to addressing prudent and economic patient-mediated needs as an outcome of qualitatively based clinical research now needs to be acknowledged and addressed, since extensive coverage of exciting treatment breakthroughs should not exclusively dominate patient management. Anxiety-provoking as it may sound, dentists must recognize that we are undergoing our own so-called systems revolution. We need solidarity in our diverse clinical research efforts to avoid regarding

biotechnologic advances as either panaceas or disruptive technology. Instead, they are welcome adjuncts for expanding qualitatively determined routine therapy.

Nico Creugers and Dominique Niesten kindly accepted the IJP's invitation to share their views on this very important topic.

Invited Commentary

Qualitative Research Is Important for All Prosthodontists

Dominique Niesten
Nico Creugers

At the Seoul meeting of the International College of Prosthodontists in September 2015, during a concurrent session in two large, well-attended lecture rooms, a problem became clear. One room featured presentations on the newest technical developments in prosthodontics. The other room's topic was geriatric dentistry, with speakers addressing the numerous problems associated with complex prosthodontic interventions in older patients. It was disappointing to note that the attendees in each room were largely unaware of the problems and challenges being discussed by the other group.

In some areas of the world, dental expectations have evolved from edentulism at a relatively young age to having a natural, probably restored, dentition into old age. The meeting on modern prosthodontic concepts addressed technical developments that would contribute to or even speed up these generally welcomed advances in dental care. However, since the efficacy and effectiveness of complex dental reconstructions are highly dependent on the recipient's neuromuscular coordination skills and cognitive capacity (1,2), and given that both of these abilities gradually decline with age, progressively diminishing at older ages, it is necessary to bring this risk more clearly to the attention of clinicians who strive to provide clinical excellence and sophisticated treatments for patients who primarily seek oral health care. Several studies have already reported gaps between what patients want and what clinicians think should be done, and these communication gaps increase with a patient's age.

In fact, dental treatment need in the eyes of clinicians is estimated to be about twice as high as that perceived by older patients (3). One way to bridge these gaps is through truly patient-centered care.

Today's focus on patient-centered care is reflected in the worldwide dental training competency prescriptions. On graduation, a dentist must "acknowledge that the patient is the centre of care, and that all interactions, including diagnosis, treatment planning, and management, must focus on the patient's best interests."(4). It appears to be as simple as that, but is this really the case? The dentist could use some help, judging from the many formal methods for involving the patient in planning oral health care. The best-known method focuses on shared decision making, where the first step engages the dentist—in fact, any care provider— in exploring a patient's specific wants and situation, together with his/her perspective on dental interventions, oral health, and oral care behavior. While this sounds commonplace, only through routine practice does it happen in an in-depth manner. Dentists need to learn to ask the right questions to find out what really matters to the patient. In prosthodontics, in contrast to what is normal in a provider-consumer relationship, the standard for care is mainly set by the professional ("clinical excellence") rather than by the patient ("personalized care"). The problem, of course, is that we are paid to deliver medical devices and not to talk about their implications.

A step further is the dentist providing the patient with the necessary information to make a genuinely shared decision possible. This may seem easy for a health care specialist, but it is more difficult than it looks. It requires better awareness from prosthodontists of the potential long-term adverse outcomes of extensive oral rehabilitations, especially when proposed and/or delivered to middle-aged or older individuals. This step requires integration of patients' wishes and situation, medical expertise, scientific evidence, and cost-considerations to develop viable care options from which a patient can choose. Unfortunately, prosthodontists are recruited only after basic oral health care has failed and therefore are dealing with high-risk patients in complex

circumstances. Prosthodontists restore dentitions that are broken down as a result of disease, expecting that rehabilitation is integral to recovery. All too often, a temporary elimination of symptoms is perceived as a successful intervention, while long-term consequences are unknown or even ignored.

To acquire the knowledge and awareness needed to successfully implement these steps, qualitative research methods at population and individual levels are indispensable. Indeed, qualitative research seeks an in-depth understanding of behaviors, contexts, and interrelationships. Evidence obtained from qualitative studies on patient perspectives can provide dentists with a better idea of what may underlie patients' wishes, and it can serve as a base for relevant questions to ask during the shared decision-making process. For instance, qualitative research has shown that older people with impaired mobility sometimes refrain from seeking dental care because they are reluctant or prefer not to overburden their social support system. In these situations, care providers could specifically ask about the social supports available and how patients think about using these supports for dental care and oral hygiene maintenance (5).

An added benefit of qualitative research is that it yields new hypotheses that can be explored quantitatively. Hence, it can strengthen qualitative and quantitative evidence on patient perspectives and treatment outcomes. Dentists can apply qualitative research techniques in their own practice, on individuals or series of patients, through asking in-depth, open-ended questions and descriptive monitoring of cases and treatment outcomes, and by analyzing this information. Sharing such findings with patients can add value to the shared decision-making process.

To optimize the outcome of patient-centered care, dentists need professional expertise and awareness of their ethical responsibility. However, these determinants must be accompanied by deep insight into their patient's perspective and circumstances—the ability to undergo and appreciate treatment responsibilities and engage in adequate oral hygiene maintenance

behavior. Qualitative research should be the key to gaining this insight, and recognizing its added value will make us all better health care providers.

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Curriculum Vitae

Dominique Jeanine Maria Niesten werd op 9 oktober 1971 geboren in Heijen. In 1983 behaalde ze haar VWO-bèta diploma aan het Elzendaalcollege in Boxmeer. Vanaf 1989 volgde ze aan de Wageningen Universiteit een Masteropleiding Milieuhygiëne, die ze in 1995 cum laude afrondde met als specialisaties aquatische chemie en aquatische ecologie. Tevens behaalde ze in 1991 en 1992 alle vakken van het eerste jaar van de bovenbouw (Master) opleiding filosofie aan de Radboud Universiteit in Nijmegen.

Tussen 1995 en 2002 werkte Dominique achtereenvolgens bij het Department of Enviroment and Heritage Protection in Cairns (Australië), Department of Natural Resources (Maryborough, Australië), Rothamsted Research (Harpenden, UK) en Subsidieadviesbureau Hezelburcht. Ze bekleedde functies als onderzoeksmedewerker, data-analist, projectmanager en subsidie-adviseur. In 2002 ging ze bij het International Office van de Radboud Universiteit werken als beleidsmedewerker en projectcoördinator. In deze functie raakte ze betrokken bij enkele grote internationale public health projecten waaraan Radboudumc afdelingen, waaronder Tandheelkunde, deelnamen. Ze maakte in 2004 de overstap naar het WHO Collaborating Center for Oral Health Care and Future Scenarios, onderdeel van de afdeling Tandheelkunde. Hier coördineerde en initieerde ze internationale onderwijs- en onderzoeksprojecten. In 2010 begon Dominique naast haar projectactiviteiten aan onderzoek naar mondzorg bij kwetsbare ouderen; dit werd in 2014 omgezet in een officieel promotietraject. Ondertussen sloot Dominique zich aan bij de onderzoeksgroep BENECOMO (Belgisch Nederlands Consortium voor Onderzoek naar MOndgezondheid) waarin hoogleraren en promovendi samenwerken om met behulp van onderzoek de mondgezondheid en mondzorg voor kwetsbare ouderen te verbeteren. Inmiddels werkt Dominique als docent-onderzoeker en coördinator van internationale onderwijs- en onderzoeksprojecten bij de afdeling tandheelkunde van het Radboudumc. Ze geeft regelmatig colleges en voordrachten over mondgezondheid van en mondzorg voor kwetsbare ouderen.

Dominique woont in Oosterhout (Gld) samen met Hugo en hun drie kinderen Jolie, Alyce en Samuel (Sam).

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